

# Assessing the Ethical and Practical Wisdom of Surrogate Consent for Living Organ Donation

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INDIVIDUALS OFTEN DECLINE TO SIGN ORGAN DONOR cards out of fear that their organs will be procured prematurely.<sup>1</sup> To reassure these individuals, procurement policy in the United States allows adults' organs to be procured only after their deaths or, in the case of nonvital organs, with their consent.<sup>2-5</sup> Despite these limitations on the procurement of adults' organs, many individuals still decline to become organ donors. As a result, US waiting lists for solid organs have grown to more than 80 000 people.<sup>6</sup>

Numerous strategies have been proposed to encourage potential donors, including payment for organs and paying for donors' funeral expenses.<sup>7-9</sup> Alternatively, some have proposed to expand the pool of potential donors by redefining death as the loss of cerebral cortex, or "higher" brain function.<sup>10</sup> Although this approach has been endorsed by some commentators, it has been rejected by all states, which continue to define death as the irreversible cessation of either cardiopulmonary function or all brain function, including brainstem function.<sup>10</sup>

Others propose to expand the pool of potential donors by allowing surrogates to donate the organs of patients in persistent or permanent vegetative state (PVS).<sup>11</sup> Surrogates might also be allowed to donate the organs of terminally ill patients who cannot make their own medical decisions. Permitting surrogates to donate the organs of terminally ill patients or patients in PVS would change organ procurement policy in 2 important ways: surrogates could donate adult patients' organs before they are legally dead and depending on which organs are donated, organ procurement might cause patients' deaths. Should these changes be introduced to current organ procurement policy?

## Risks to Individual Patients

Keeping patients alive and procuring their organs over time, essentially turning patients into support systems for spare organs, seems too horrific to contemplate. To avoid this scenario, surrogate consent for living organ donation should be permitted only when an appropriate surrogate has de-

cidated to remove life support from patients who are expected to die without it.

Unfortunately, it is impossible to determine with certainty whether a given patient will die following withdrawal of life support.<sup>12</sup> In one study, 6 of 166 patients who were expected to die following the withdrawal of mechanical ventilation survived and left the hospital.<sup>12</sup> To minimize the risks to these patients, surrogate consent for living organ donation should be limited to patients whose underlying conditions preclude recovery.

Patients with the least chance of recovery are perhaps those in PVS, an unconscious state in which patients retain at least partial brainstem autonomic function but have no awareness of themselves or their environment due to global loss of cerebral cortical function.<sup>13,14</sup> Vegetative states lasting longer than 1 month are considered persistent; those lasting more than 3 months after a nontraumatic injury or more than 12 months after a traumatic injury are considered permanent.<sup>14</sup> Patients in PVS require artificial nutrition and hydration; some also require ventilatory support. With these interventions, median survival for patients in PVS is approximately 2 to 5 years.<sup>14</sup>

Supporters of surrogate consent for living organ donation argue that patients do not have an interest in simple biological existence absent all consciousness. They conclude that procurement of organs would not harm patients in permanent vegetative state.<sup>11</sup> Unfortunately, despite the label of *permanent* vegetative state, it is impossible to determine whether a given instance of PVS truly is permanent.<sup>13</sup> Consider a recent example. For 19 years, while Terry Wallis remained in PVS, his family sat by his bedside and engaged in 1-way conversation.<sup>15</sup> One day in 2003, Terry spontaneously and unexpectedly called out to his mother. The next day, in response to a direct question, Terry stated that he could say "anything you want." While rare, and unlikely to result in normal neurological function, such recoveries reveal that surrogate consent for living organ donation even when limited to patients in PVS poses some risks to the real, albeit extremely remote possibility that the patient will eventually regain consciousness.

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See also p 728.

Presumably, the chance that patients in PVS will regain consciousness between the time life support is withdrawn and death occurs is very close to zero. Hence, allowing procurement of organs only when an appropriate surrogate has independently decided to withdraw life support would minimize the risks to patients. In these circumstances, surrogates might choose to donate the organs of patients in PVS, despite the risks it poses to the patient's extremely remote chances of recovery, on the grounds that organ procurement is consistent with the patient's preferences.

### Difficulties With Substituted Judgment Decisions

Barring designation of an "organ donation" surrogate, clinical care surrogates, whether assigned formally by the patient or identified through state guardianship hierarchies, would have to make living organ donation decisions. Current legal and ethical norms specify that clinical care surrogates should base their decisions on the substituted judgment standard. When surrogates do not have enough evidence of patients' preferences to make a substituted judgment decision, they should base their decisions on the best interests standard.

According to the substituted judgment standard, surrogates should choose the option that the patient would have chosen if competent. Surrogates can attempt to determine which option the patient would have chosen by appeal to 3 different levels of evidence: explicit formal evidence, such as an advance directive; explicit informal evidence, such as unambiguous conversations with the patient; and implicit evidence, such as knowledge of the patient's character.

Data regarding use of advance directives for clinical care, research participation, and organ donation reveal that surrogates rarely have explicit formal evidence of individuals' preferences. Despite overwhelming public support for formal advance directives, only approximately 20% of individuals complete one.<sup>16,17</sup> Furthermore, more than 90% of advance directives are limited to directing surrogates to withdraw life support when there is "no hope" for a quality life.<sup>18</sup> These data suggest that, even when present, advance directives are unlikely to specify patients' treatment preferences when there is a remote chance of recovery. Also, the few forms that specify patients' preferences in the face of an uncertain prognosis rarely provide definitive evidence of the choices the patient would have made in the actual clinical circumstances.<sup>19</sup>

Theoretically, surrogates could appeal to explicit informal evidence of patients' preferences to address these deficiencies with formal advance directives. However, data show that most individuals do not discuss their end-of-life preferences with their surrogates or physicians.<sup>20-22</sup> On the assumption that individuals are no more likely to discuss their preferences regarding living organ donation, surrogates are unlikely to possess explicit informal evidence on which to base living organ donation decisions.

While much easier to obtain, implicit evidence, such as evidence of a patient's character or way of life, is even less

likely to provide accurate guidance regarding living organ donation. Individual patients' living organ donation preferences, like their preferences regarding end-of-life care, depend on multiple and complex factors, including fear of death, trust in the organ procurement system, and belief in an afterlife. The fact that a patient devoted substantial time to charitable activities, for instance, provides little evidence about whether he/she would be willing to help others by donating organs before death.

In the absence of explicit evidence, surrogates must guess what decision the patient would have made in the circumstances. Yet, existing data suggest that surrogates are only somewhat better than chance at predicting patients' wishes at the end of life.<sup>23-26</sup> Furthermore, the stress, sorrow, and uncertainty that accompany caring for patients at the end of life raise the possibility that actual surrogate decisions may be even less reliable than those based on hypothetical scenarios.<sup>27</sup> Finally, supporting a loved one at the end of life can be very burdensome, raising the possibility that surrogates' decisions may be affected, even unconsciously, by their other interests.<sup>28,29</sup>

Allowing surrogate consent for living organ donation only when surrogates have compelling formal evidence of patients' preferences would minimize the chances that procurement decisions will conflict with patients' preferences. However, given that only about 20% of individuals complete a formal advance directive, and few formal advance directives document patients' preferences regarding organ donation, this approach would yield extremely few organs. Alternatively, policy might stipulate that, in the absence of clear evidence regarding patients' wishes, surrogates should use the best interests standard.

### Difficulties With Best Interests Decisions

The best interests standard specifies that surrogates should make decisions based on what is in the patient's best interests. With this in mind, one might defend surrogate consent for living organ donation for patients in PVS on the grounds that individuals have an interest in contributing to worthy causes. A medical instructor's overall life seems richer when she inspires her students to help the poor, even when she never learns of her students' good work. Similarly, proponents of surrogate consent for living organ donation might argue that patients' overall lives are richer when they help others through donation of their organs, even when they do not realize the donation has occurred. Through organ donation, patients contribute to the noble cause of saving other people's lives.

Students' good work reflects on their teachers' lives because the teachers actively taught the students and encouraged them to do good work. In the absence of an explicit advance directive, patients in PVS contribute to saving others only passively; their organs are harvested and transplanted into others, without their active consent or involvement. Such passive contribution seems to say little about

the patients' lives, promoting their overall interests in a minimal way, if at all. Hence, even if the risks to patients in PVS are minimal, the best interests standard does not seem to support procurement of organs when the patient's preferences are unknown.

### Threats to Public Trust in Organ Procurement

In addition to the risks to individual patients, surrogate consent for living organ donation may pose risks to organ procurement in general. Many individuals oppose and current policy prohibits physicians from causing patients' deaths for the patient's own benefit through euthanasia. In this context, allowing physicians to cause patients' deaths through organ procurement seems contradictory and may dramatically undermine public support for organ procurement programs. This possibility suggests that surrogate consent for living organ donation, if adopted at all, should be restricted to the procurement of nonvital organs.

Allowing surrogates to donate the nonvital organs of terminally ill patients has the potential to undermine trust in both medical care and organ procurement. Because there are no clear standards for determining when patients are terminally ill, it would be impossible to assure the public that a policy allowing surrogate consent for living organ donation for terminally ill patients would not expand to other patient groups, such as patients with Alzheimer disease. In addition, Americans tend to be wary of the possibility that decisions to withdraw life support may be influenced by factors other than what is best for the patient, including what is best for those in need of an organ transplant.<sup>30</sup> Without assurance that organs will be procured only with their consent or death, potential donors may decline to sign donor cards, leading, in the long run, to fewer available organs. These concerns reinforce the conclusion that, at most, surrogate consent for living organ donation should be limited to patients in PVS.

### Benefits of Surrogate Consent for Living Organ Donation

To evaluate fully the ethical and practical wisdom of surrogate consent for living organ donation from patients in PVS, it is important to assess how many organs it might yield. The limited available data on PVS suggest that any assessments in this regard will be speculative. Jennet<sup>31</sup> reports prevalence of PVS at approximately 50 per million population, implying that there may be up to 14 000 individuals in PVS in the United States at any time. Assuming patients in PVS survive about 4 years on average (reported range, 2-5 years), the annual incidence of PVS is approximately 3500.

Many of these 3500 individuals would be inappropriate organ donors because of their underlying diseases. Hypoxic ischemic encephalopathy, a leading cause of PVS, is likely to cause organ degradation in some cases and patients with infectious encephalopathies are ineligible to do-

nate their organs.<sup>14</sup> If one assumes that 50% of individuals in PVS are potential donors and 2 organs can be procured on average from each donor, procurement from individuals in PVS has the potential to yield at most 3500 organs per year.

Presumably, surrogates will not give permission to procure organs in every case, further reducing the total number of organs obtained. It seems unlikely that the percentage of eligible individuals in PVS from whom organs would be procured will be higher than the percentage of eligible cadaveric donors from whom organs are ultimately procured—approximately 42%.<sup>32,33</sup> This suggests that surrogate consent for living organ donation may yield at most 1500 organs per year (3500 patients, 50% of whom are eligible to donate 2 organs with a 0.42 procurement rate).

Even a figure of 1500 organs a year may be overly optimistic. First, any safeguards that require explicit evidence of patients' wishes will further reduce the number of organs procured. Second, many organs obtained through surrogate living donation could have been procured after the patient's death. Consequently, surrogate consent for living organ donation may not generate a net increase in organs. More likely, it will yield healthier organs that have not experienced the ischemia associated with cadaveric procurement. In the end, depending on precisely which safeguards are adopted, surrogate consent for living organ donation might yield between several hundred and 1500 healthier organs per year.

While important, these benefits barely begin to address the needs of the 80 000 individuals on waiting lists for solid organs. In contrast, allowing surrogates to donate the organs of individuals in PVS poses some risks to individual patients and threatens to undermine trust in organ procurement in general, possibly reducing the overall number of organs procured. These considerations suggest that surrogate consent for living organ donation would make for unwise public policy.

### Safeguards for Surrogate Consent for Living Organ Donation

If surrogate consent for living organ donation is pursued despite the serious risks and modest benefits, 9 safeguards should be adopted to minimize the risks of abuse.

First, surrogate consent for living organ donation from patients who are unable to make their own medical decisions and thought to be terminally ill poses clear risks to these patients and could dramatically undermine trust in medical care. Hence, surrogate consent for living organ donation should be limited to patients in PVS.

Second, organ procurement should be limited to nonvital organs. Currently, many people oppose causing patients' deaths for their own benefit. In this context, allowing physicians to cause patients' deaths by procuring vital organs could dramatically undermine support for organ procurement.

Third, the specter of keeping patients alive to harvest their organs over time seems horrific—the equivalent of organ farming—and would almost certainly undermine public support for organ donation. Consequently, living organ donation should be allowed only when the appropriate surrogate has decided to withdraw life support for reasons independent of organ donation.

Fourth, there should be compelling evidence, such as positive apnea test results or a decision to stop nutrition and hydration, that withdrawal of life support will lead imminently to the patient's death.

Fifth, there should be good reason to believe that the procurement of organs prior to death offers a clear advantage, typically in terms of healthier organs, compared with procurement after the patient's death.

Sixth, a family member or close friend, assigned by the patient or based on state law, must consent to removal of the patient's organ(s).

Seventh, a trained clinician, independent of the clinical and procurement teams, should ensure that the surrogate understands the patient's prognosis and the nature of organ procurement, does not have any clear conflicts of interests, and has sufficient evidence that procurement is consistent with the patient's competent preferences.

Eighth, to minimize conflicts of interest, surrogates should not receive financial compensation, and the organs should not go to the surrogate or family, either directly or through organ exchange programs.

Ninth, surrogate consent for living organ donation should be allowed only in a context that informs the public of this policy and provides a mechanism for those who oppose living organ donation to document this preference.

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