



NATIONAL CATHOLIC PARTNERSHIP ON DISABILITY

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John R. Lake, M.D.

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OPTN/UNOS

700 N. 4th St.

Richmond, VA 23218

June 15, 2012

Re: Proposed changes to the DCD Model Elements

Dear Dr. Lake:

I Chair the National Catholic Partnership on Disability (NCPD). NCPD was established thirty years ago to implement the *Pastoral Statement on People with Disabilities* of the U.S. Catholic bishops. On behalf of NCPD and the fourteen million Catholics with disabilities it serves, I urge UNOS to reject the proposal for changing the DCD Model Elements.

The proposed changes aim “to maximize the number of donors and transplants by identifying ... currently unrealized donor potential [.]” As laudable as that objective is, it cannot justify singling out a class of disabled people, those dependent on life-support, for adverse treatment. Under the proposal, for example, the hospital and local OPO may examine patients on life-support to determine their eligibility for organ donation without their knowledge or consent, even though they are neither terminal nor near death. Further, the hospital may initiate a request for donation of such patient’s organs before the decision to withdraw life-support is made. Finally, the OPO is not required to condition eligibility for organ donation on assurances that a conscious patient’s decision to have life-support withdrawn is voluntary and not a product of clinical depression.

Simply put, the proposed changes subject a class of disabled people to discriminatory treatment, while offering justifications that are inapposite, unconvincing, and clearly violative of patients’ rights.

The proposal imposes specific rules that OPOs and transplant centers must follow. If approved by the Secretary of HHS, such rules become conditions of participation in the OPTN and, in effect, revisions of existing law. See 42 C.F.R. §§ 482.45(b)(1).

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The proposed changes expand “potential DCD donor” beyond patients with permanent and irreversible neurological injury to include those whose “disease” renders them dependent on life-sustaining medical treatment or ventilated support. “Disease” was added to allow “patients that do not have a neurological injury, but a disease that render[ed] them ventilator dependent ... to grant first person consent for donation [.]” Given the ease in which patients on life-support can already donate their organs, *see Revised Uniform Anatomical Gift Act*, §5 (2008), one may ask why an admittedly “rare” occurrence should occasion a major expansion of donor criteria. In any event, the text is ambiguous on whether “permanent and irreversible” qualifies only neurological injury or applies to disease as well. And contrary to the proposal’s explanation, the language is not in fact limited to conscious patients or those on ventilated support.

The proposed changes require participating hospitals to be Medicare and Medicaid certified. Under CMS regulations, such hospitals “must notify, in a timely manner, the OPO ... of individuals whose death is imminent or who have died in the hospital.” 42 C.F.R. §482.45(a)(1). The proposal expands this duty to include patients on life-support, regardless of whether their death is imminent or whether they have offered to donate their organs.

Under existing law, “The OPO determines medical suitability for organ donation [.]” *Id.* Given the expanded donor class, the proposal further provides that “The primary healthcare team and the local OPO must evaluate potential DCD donors to determine if ... [they have] a permanent and irreversible neurological injury, or disease which may allow for a planned withdrawal of life-sustaining medical treatment or ventilated support.” This language is sufficiently broad to authorize a physical examination, as well as a record review, without requiring that patients’ or their families’ know or consent. In the absence of some offer to donate, the provision would most certainly violate patients’ rights to be free from unwanted medical procedures.

The proposed changes erroneously rely on CMS regulations and the UAGA for support. As the proposal itself recognizes, CMS regulations require hospitals to report only those patients “whose death is imminent, or who have died [.]” *Id.* Likewise, UAGA’s authorization for physical examination of potential donors is limited to patients, referred to procurement organizations, who are “at or near death [.]” *Revised Uniform Anatomical Gift Act*, §14(a-c).

Conceding that referral for evaluation may occur “prior to family knowledge of donation options,” the proposed changes offer two primary justifications: First, “the evaluation of a patient as a potential organ donor can be facilitated without OPO communication with the family [;]” second, “the patient may have already been registered as an organ donor, which requires no further authorization by a surviving family or caregiver.” It should go without saying that, if patients have the right to be free from unwanted medical procedures, they or their families also have the right to know when such procedures take place. Further, even if staff can examine registered donors without further authorization, that provides no support for such examination where an offer to donate has never been made.

The proposal contends that, “by not allowing for an OPO’s evaluation for donor candidacy prior to a decision to withdrawal (sic),” the health care system will in some way mislead families into believing that “their loved one is not a donor candidate, when in fact they (sic) might be” or that “they are authorized to make donation decisions for the individual at or near death, while in fact they may not be.” Of course, it is hardly misleading to say nothing unless one has a duty to speak. But there can be no duty to inform families that their loved ones are donor candidates if that entails violating patients’ rights not to be examined without knowledge and consent. And whether the OPO is obliged to inform families that they are not authorized to make donation decisions, because, for example, a refusal record was found during a search of a patient near death, *see Revised Uniform Anatomical Gift Act*, §12(a), that says nothing about OPO’s obligation when death is not imminent. Finally, examinations to determine donor eligibility without family knowledge and consent may well expedite “withdrawal procedures as agreed to by ... [such] family [;]” but this would simply justify violation of patients’ rights by reference to the benefit it may produce.

Though agreeing that “ethical concerns and safeguards are paramount in the organ donation process [;]” the proposal nonetheless rejects the IM recommendation that “the decision to withdraw life-sustaining treatment should be made independently of and prior to any staff initiated discussion of organ and tissues donation.” Committee on Non-Heart Beating Transplantation [ii](#), Institute Of Medicine, *Non-Heart-Beating Organ Transplantation: Practice and Protocols* 16 (National Academy Press 2000). It claims instead that patient protection will increase by ensuring that “hospitals and caregivers have a policy and ... that OPOs and Transplant Centers abide by the policies developed.” Of course, requiring “a policy” without specifying what that policy contains is an empty gesture. And the two safeguards the proposed changes actually require, that “no member of the Organ Recovery team or OPO staff may guide or administer palliative care, or declare death” and that “no member of the Transplant Center surgical team may be present for the withdrawal of life-sustaining medical treatment or ventilated support [;]” provide scarcely more protection from pressure for families considering withdrawal. The former applies after the decision to withdraw life-support is made; the latter, besides inexplicably omitting OPO staff, comes at a time when family may not even be present rather than the time they are most susceptible to pressure, when they are wrestling with whether to withdraw life-support.

The proposal acknowledges that patients with chronic illnesses are “vulnerable to real or perceived pressure to decline further treatment in order to donate their organs, especially since the Requirements would permit evaluation of their eligibility for organ donation in advance of a decision whether to withdraw ventilatory or other life-sustaining support.” Nevertheless, it rejects psychiatric evaluations, waiting periods before withdrawal occurs, and other safeguards to ensure valid consent, claiming that these are policies for the hospital to prescribe, “[i]ndependent of the option for organ donation[.]” Given the likely impact the proposed changes will have on the decision to withdraw life-support, the claim that procedures

overseeing donation and withdrawal are independent and that “[t]he separation of the OPO and Hospital responsibilities related to these assessments further safeguards patient autonomy and decision-making” is plainly facetious. Without effective safeguards, like the rule the IM recommends, to ensure that patients or families make the withdrawal decision voluntarily, the proposal’s assurance of patient protection is merely “a promise to the ear to be broken to the hope.”

The proposed changes no longer expressly list those with specific disabling conditions, “end-stage musculoskeletal disease, pulmonary disease ... [and] upper spinal cord injury” as potential DCD donors. Even so, patients dependent on life-support certainly have “a physical or mental impairment that substantially limits one or more major life activities,” 45 C.F.R. §§ 85.3, and thus are “handicapped” for purposes of federal civil rights law. Under regulations implementing the 1978 Amendments to the Rehabilitation Act, HHS “may not, directly or through contractual or other arrangements, utilize criteria or methods of administration the purpose or effect of which would [s]ubject qualified individuals with handicaps to discrimination on the basis of handicap[.]”/§85.21(b)(3)(i).

Clearly, the proposal identifies patients on life-support as “the currently unrealized donor potential [.]” It “would maximize the number of donors and transplants” by permitting staff to examine such patients without their consent. It would permit staff to approach patients or families, before they decide to withdraw life-support, to inform them that the patient’s condition allows “for a planned withdrawal of life-sustaining medical treatment or ventilated support” and discuss the options for organ donation once the patient is dead. Further, it would not require assurances, as a condition for donor eligibility, that a conscious patient’s decision to withdraw life-support is voluntary and not a product of clinical depression. It is hard to avoid the conclusion that the proposed changes target patients on life-support because they are considered more valuable when dead.

In our November 9, 2011 letter, we cautioned that adoption of the then proposed changes “would cause many within and outside the disability community to question UNOS’ continued oversight role under its contractual arrangements with HHS.” Regrettably, the present proposal gives us no reason to alter that belief.

Respectfully submitted,

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Chair
National Catholic Partnership on Disability