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## Going too extreme

\_Viewpoint

The shortage of organs and tissues facing those awaiting transplantation is tragic and all too real. As of October 8, 2010 there were 117,925 persons in the United States wait-listed for kidneys, hearts, livers, lungs and other organs.<sup>1</sup> Most will die without getting a transplant. And, the waiting-list in America would be bigger if persons with cognitive impairments, drug problems, prisoners, the uninsured, and the very old who are dying of organ failure were added.

This situation prevails all over the world. The need for organs is great and growing. This has led to calls for all manner of changes in the policies governing organ donation. Should the need of those dying for want of organs lead to revisions in the long standing ethical framework governing donation that rests upon altruism and voluntary donation?

### Donation trumping advance directives

Efforts have been made in the USA to change the law governing organ donation, the Model Uniform Anatomical Gift Act Organ. The changes would give more weight to the desire to donate organs than to following the requests of those who are dying as to how they want their medical care managed.

A number of states in the USA have passed laws allowing organ donation requests to trump what patients have said about discontinuing life-support on living wills or advance directives [5]. The proposed revisions make it impossible to discontinue life-support if organ donation were deemed a possibility even if there are explicit instructions to the contrary from the patient.

These laws presume the dying person would make organ donation a higher priority than the humane management of their own dying. Some persons may indeed make that choice but it is a choice that ought to be explicitly made, not presumed and certainly not legislated as the default when conflicting instructions are given.

### Registries without a choice

States in the USA are also adopting organ registries through the bureau of motor vehicles, which give an opportunity for citizens to register their preferences for organ donation. The organ transplantation community has publicly emphasized autonomy as the justification. Families, they have argued, should not overrule donor preferences. Indeed, some states would penalize physicians for not «honoring» registered donor preferences [6].

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In some states, there is no opportunity to register a refusal to donate.<sup>2</sup> This allows procurement personnel to approach families of persons who did not want to donate but did not have the same opportunity to say so in writing. And some states, such as New Jersey, have made an answer to the question of organ donor donation required in order to secure a driver's license or to renew one. It is not clear why someone must answer a question about organ donation in order to be deemed qualified to drive a car.

### Conflict of interest

From its early days, transplant policy in the United States and in nearly every other nation with a donation system made a clear division between those health professionals with responsibility for the best interests of very sick patients with healthy organs and those responsible for very sick patients who needed healthy organs.

In some organ and tissue banks in the USA, those involved on the frontlines of procurement have been paid incentives if they procure the most organs or tissues in a given month or year. Does this practice guarantee sensitivity to the deceased or the deceased's family's interests? Such approaches edge toward the creation of an unacceptable conflict of interest as they more closely resemble schemes to pay a bounty for parts rather than a salary paid to those who are responsible for protecting the interests of donors.

Increasingly, those who request organs and tissues are attempting to approach families before their loved ones are dead. Some organ procurement teams are subtly shifting the criteria by which death is pronounced in order to maximize the odds of obtaining a transplantable vital organ [7, 8]. In the area of donation after cardiac death donation protocols are in place in the USA whose sole originators are transplant teams desperate to find hearts for infants on waiting lists [8].

### Changing the time-honored model of informed consent

The moral and legal doctrine of informed consent governs decision making with patients and research subjects. So too, has it governed the interaction when procurement personnel request tissue donation from families of recently dead loved ones. Usually, these requests come from strangers over the telephone. The transplant community is moving to reject the model of informed consent in favor of «authorization», a term they have yet to define. Their justification is that le-

1 <http://optn.transplant.hrsa.gov/latestData/rptData.asp>2 <http://www.coloradodonorregistry.org/>

gally, informed consent deals only with living patients and research subjects. But, this is nonsense. Families have just as much right to provide full, informed consent as would the deceased.

### Markets

There are many proponents of various schemes of organ vending pushing this idea [1] [2, 9, 10]. The fact that all available evidence shows that markets cause far more harm than good and are difficult to police [11, 12] seems not to register with those for whom markets are the iconic answer to all forms of shortage. They seem indifferent to the fact that major religious groups have made it clear that they will oppose and not participate in any system of organ and tissue procurement that involves the sale of the human body and its parts. Nor do they seem responsive to the huge inequities in access that markets in China and India have brought in their wake. And there is no acknowledgement that the long history of racism and exploitation of poor minorities by wealthy nations makes it likely that proposals to pay for parts may create animosity rather than an increase in supply.

The case for turning to markets is built on the presumption that the right financial incentive will motivate those who are unwilling to provide organs freely to do so. But, the empirical evidence does not support the view that it is money which is the primary obstacle to getting organs for transplant. In the USA those pushing for markets in the name of helping the poor have said remarkably little about finding forms of insurance to permit the poor to access transplants – an inequity that hinders the willingness of the poor to be donors since they resent being organ sources for the rich.

### Conclusion

The ongoing shortage in organs for transplantation has led many to call for changes in the traditional ethical framework that has governed organ donation – voluntary altruism on the part of donors and the ‘dead donor rule’ in terms of eligibility for contributing a vital organ. As these proposals are considered it is important to keep in mind the fragile basis of public support for organ and tissue transplantation. It is also important not to compromise the available supply of organs in the hope of pursuing a new policy that engenders significant public mistrust that may translate into opposition to donation. Organ donation rests on a very tenuous base of public trust. Radical departures from current practice, even if motivated solely by a desire to save lives that otherwise will be lost, imperil that requisite trust.

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