Decisions about organ donation should rest with potential donors, not next of kin

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Organ transplantation is one of the most important advances in acute care medicine in the last 30 years. It allows people who would otherwise die or have a miserable quality of life to lead normal and productive lives — if they can get an organ.

That is a big if. At any given time dozens of people are waiting for a new lease on life, but many of them won’t get it because not enough organs are available. That is why transplant societies are doing their best to raise organ-donor awareness and why they work continually to improve recovery and transplantation techniques. The current shortage means that no organ may be wasted.

Transplant societies have also tried to make the shortage less severe by suggesting that family physicians discuss organ donation with patients and make a stronger effort to educate them about the benefits enjoyed not only by recipients but also by society and the health care system in general because transplantation is cost-effective.

They have also proposed the establishment of donor registries that would list everyone who has agreed to be an organ donor. When a potential organ donor is dying it would be known immediately if the person had agreed to donation. This would mean that more organs would be recovered.

Finally, the societies have suggested that the laws governing organ donation be changed. The explicit consent that is currently required would be replaced with a general presumption that everyone has agreed to organ donation save for those who have completed a form saying they do not want their organs removed after death. These changes would bring Canadian laws into line with those currently in place in France and elsewhere.

However, there is already a supply of organs available that does not require the establishment of a registry or a change in existing laws. The only requirement is that transplant societies honour the ethics of informed consent and follow existing organ-donor laws.

More precisely, provincial and territorial acts concerning the gift of human tissue state that the consent of a competent person provides “full and binding” authority for the removal of organs for transplantation. On the one hand, “full” means that if someone has consented to the removal of organs, no one else needs to be asked for permission to remove them. On the other hand, “binding” means that no one else may overrule the consent of the donor and substitute his or her own wishes.
Almost without exception, however, organ-retrieval protocols of Canadian transplant societies state that consent of the donor’s next of kin is required for organ retrieval even when the donor has given explicit consent and there is a donor card or sticker. They further state that if the next of kin refuse to provide consent, the organs should not be retrieved.

For example, guidelines on organ and tissue donation prepared by the Multiple Organ Retrieval and Exchange Program of Ontario state: “A signed driver’s licence/donor card is considered a legal document but it is the practice of the transplant programs to follow the wishes of the next of kin. If the next of kin refuse consent for organ and/or tissue donation their wishes must be respected.”

Similarly, a manual developed in BC states: “Consent for organ donation is required from the attending physician, next of kin and the coroner.” It adds: “Although a driver’s licence or document form when signed is considered a valid and legal document permitting organ donation, the next of kin are always approached. If they decline the option of donation, no pressures are exerted to convince them otherwise.”

These protocols clearly ignore current organ-donor laws and the organ shortage is greater than need be because of them. Every organ that is not retrieved represents not only a potential death or continued disability but also an increased drain on society’s health care resources.

The retrieval protocols also raise serious ethical issues. In effect, the societies are saying that they do not consider informed donor consent to be binding. The societies have argued in favour of the protocols by saying that if they retrieved organs against the wishes of next of kin, they would be perceived as ghouls. This would cause negative publicity that would lead to a drop in the number of organ donations (Dr. D. Boyes, Minister’s Advisory Committee on Ethical Issues in Health Care, Vancouver: personal communication, 1995). That is why they have proposed the donor registry and suggested changing the law to one of presumed consent instead of following current laws and honouring the ethics of informed consent.

Unquestionably, an organ-donor registry would be useful, as would the proposed change in legislation. Unfortunately, neither comes to grips with the real issue: Is it the potential donor who has the right to decide what shall happen to her/his body, or is it someone else? Does informed consent count, or doesn’t it?

Furthermore, neither proposal from the transplant societies would change the situation. A registry would be useful only if registered donors actually had their organs retrieved upon death. However, a registry could not ensure that this would actually happen — this would depend on local retrieval protocols.

Even if the legislation changes, next of kin might still refuse permission for organ retrieval. Unless a new law meant that next of kin would not be asked for their consent, there would be no guarantee that the number of retrievals would increase.

Therefore, the proposed laws would work only if the transplant societies acted the way they are supposed to (even under existing laws). Unfortunately, given current retrieval protocols, there is considerable justification for doubting that this will in fact happen.

Physicians are caught in a vise of ever-increasing resource limitation that affects the quality and availability of health care. Governments are usually blamed for this, but in the case of donor organs the fault lies within the health care community itself.

I am not saying that following the law and the ethics of informed consent will eliminate the current organ shortage. However, the shortage would not be as bad as it is if donated organs were in fact retrieved, if the wishes of potential donors were followed and if the ethics of informed consent were taken seriously.

When every donated organ might represent a life saved, can one afford to be less than ethical?