Presumed consent! Let’s not be presumptuous!

In his winning 1997 Logie Medical Ethics Essay “Organ procurement: Let’s presume consent” (CMAJ 1998; 158[2]:231–4), Dr. Fady Moustarah proposes that Canada adopt a presumed-consent model for the procurement of organs. He writes that many people who support organ donation find it hard to contemplate donation because it is difficult for them to envision their own deaths. He then argues that society err by assuming that the absence of expressed consent implies a refusal to donate. “Alternatively,” he writes, “presuming consent allows us to meet better the wishes of most people. Hence, presuming that the majority favour organ donation is the morally correct way to proceed because it finds its roots in the recognition of the unexpressed but autonomous will of most members of society. . . . In other words, it would be safe to assume that people who have not registered an objection want to donate their organs” [emphasis in original].

What to think of this proposal? Many of us do indeed have difficulty envisioning our own deaths. I suspect this is central to our humanness: it reflects our capacity to feel, think, reason and “project futures.” I’m not sure, though, that the difficulty I may have envisioning my own death leads me to struggle with the question of organ donation.

Further, Moustarah may well be right in suggesting that those who have not signed their organ donor cards in fact think organ donation is good. But to move from this claim to a presumption that their organs are there for the taking is, quite simply, wrong. Even more troubling is his suggestion that this practice can be justified on ethical grounds as a reflection of “the unexpressed but autonomous will of most members of society.” What might this mean? Why should my silence — the fact that I haven’t signed my organ donation card — be interpreted as consent to take my organs? My silence says more about my ambivalence than anything else. To suggest that my silence is really my “unexpressed but autonomous will” and to conclude that I really want to donate my organs because I have not “registered an objection” is presumptuous and disrespectful — a classic non sequitur.

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Dr. Moustarah notes the following important truths about organ donation and organ donors: “[W]e err when we assume that the absence of expressed consent implies a refusal to donate” and “not every person who fails to sign a card is an objector [to organ donation].” These truths — that some people who would agree to be organ donors fail to sign their donor cards and fail to discuss this important issue with those who might need to make a decision about cadaveric organ donation for them — underscore the need for effective public education about the importance of taking these necessary steps. In Canada, cadaveric organs can only be removed with the prior consent of the donor or the next of kin. And for Moustarah, therein lies the problem.

He believes that public education will not alleviate the shortage of organs and the need for rationing. And so, with the explicit goal of increasing the number of cadaveric organs available for transplantation, he enjoins us to replace the current false assumption about the beliefs and values of non-donors with another equally false assumption — that since a majority support the practice of organ donation we should assume that they want to participate in the practice and want to donate their organs.

This assumption is both seriously flawed and dangerous. For example, it would mean that because most members of society support intensive care units (ICUs) we should presume consent and act on the “unexpressed but autonomous will” of anyone who might medically benefit from this type of care. Moustarah has failed to recognize that even though many practices are “desirable and noble,” including transplantation and ICU care, some reasonable, autonomous people will still choose not to participate in them. To suggest that societal approval of a practice can be construed as unexpressed individual autonomous consent to participation in that practice is simply false and borders on tyranny. Furthermore, we need to be particularly wary of arguments suggesting that presumed consent better protects individual autonomy than expressed consent.

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Where’s the evidence for home care?

The article “Evidence-based rationing: Dutch pragmatism or government insensitivity?” (CMAJ 1998;158[2]:213–4), by Drs. Stuart M. MacLeod and John Bienenstock, raises cautionary flags. However, it also demonstrates the pitfalls of not