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VIEWS & REVIEWS

PERSONAL VIEW

Marketing to register organ donors may circumvent principles of informed consent

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Organ donation and transplantation are seen as indisputable medical successes that are a communal moral good. Twin themes dominate the public debate: low organ supply is creating a preventable health tragedy, and increasing supply will solve the growing problem of organ failure. Health education and marketing campaigns to boost donation rates accompany the public debate, and they typically use emotive and persuasive language (“gifts of life”; “joy from tragedy”) to assert the worth of donation and transplantation. Ultimately, their aim is to secure advance consent from potential organ donors through registries.¹

Current and prospective medical decision making relies on five well established criteria: competency; disclosure of material information; optional and voluntary participation; understanding the nature, risks, and benefits; and participation without coercion. Together these criteria form the doctrine of informed consent that lends ethical legitimacy to healthcare interventions through respecting patient autonomy.² For posthumous organ donation, consent is sought from the dead person’s substitute decision maker at the time of organ harvesting. The donor registry indicates the wishes of the dead person and so provides a form of advance consent.

Increasing donor registrations through marketing campaigns compromises three of the five principles of informed consent. Firstly, the competency of donors is not assured at the point of registration. Secondly, public information at the point of registration usually excludes the known risks associated with donation and transplantation. Thirdly, the portrayal of an organ shortage as a communal crisis to be solved by individual altruism may be viewed at best as paternalistic and at worst as a contemporary form of coercion.

It is curious that the ethics of direct marketing to secure advance consent for organ donation has not been challenged. Ideally, informed consent should be secured in an environment free from external pressure. The transplant community is proactive in its use of the media to positively influence public attitudes towards organ donation, often using sympathetic organ donation stories.¹ Although this is seductive in terms of the pragmatics of

increasing the number of those on the register, it relies on giving incomplete, and therefore biased, information. When coupled with a strong call for communitarianism not seen in other areas of medicine that rely on advance consent, this may create a coercive environment.

The benefits of organ and tissue transplantation are undeniable and are justifiably prominent in educational and marketing materials to potential registrants. Less visible are the known negative consequences for donor families and recipients. Present in a dispersed yet considerable literature these include a range of post-transplant illnesses and poor physical and psychological health.³⁻¹⁰ In a significant departure from other forms of advance decision making in medicine these known risks remain largely absent from public view.

The critical step that is missing in registering to be an organ donor, in which it differs from other forms of medical advance decision making, is a conversation with a healthcare worker to assess information needs, clarify misunderstandings, and ensure the prospective donor’s competence to make such a significant decision. Requiring this would bring advance consent for organ donation into line with the principles of informed consent, which form the basis of best clinical practice. Current registration practices influenced by biased marketing strategies may deny potential donors the important opportunity to access balanced comprehensive information.

Does the public benefit of donation and transplantation outweigh the necessity of following the usual conventions for informed consent? It is difficult to think of any other area of medicine where such a pragmatic approach, under the assumption of a greater good, has so visibly eroded the principles of informed consent. Two possible reasons for this may be identified. Firstly, the dead donor is precisely that: dead. There may be an assumption that a dead person cannot be harmed. There is ongoing debate over whether dead people can be harmed or not,¹¹ but current Western conventions respect the wishes of dead people and ascribe to them posthumous rights to privacy and dignity. It is, therefore, reasonable to conclude that

consenting to something that will occur after death, while you are alive, should be treated within the usual parameters of informed consent extended to the living.

Secondly, the broader public benefit may be so strong that informed consent at the point of registering to be an organ donor can be overlooked. Clearly there is high individual benefit for recipients; some potential benefits to donors from the altruistic act of gifting; and some identified savings to the public purse for those who no longer need intensive medical care.¹² However, cost savings are offset by the expense of publicity campaigns, the training and allocation of clinical staff, maintaining dead donor viability in intensive care units, and the ongoing treatment of recipients after transplantation.

It is debatable whether the individual benefit to be gained from organ transplantation is of such high worth to society that it is permissible, and indeed necessary, to deny the donor the same ethical safeguards of informed consent that define advance decision making in other areas of medicine. In the case of informed consent to register as an organ donor, pragmatism seems to be over-riding protective ethical principles.

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