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Registering wishes about organ and tissue donation: personal discussion during licence renewal may be superior to online registration

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Abstract

Consent to organ and tissue donation is higher when the deceased has indicated a wish to donate. The Australian Organ Donor Register (AODR) is the national register of preferences regarding donation. The AODR has a number of limitations; it has no mechanism for requiring individuals to register their wishes, while the online format both raises concerns about the validity of the consent obtained and precludes personal discussion of fears and concerns about donation. A solution to these limitations is to utilise state-based agencies that administer driving licences. This strategy ties the

donation decision to an existing task (renewal of driving licences), and provides an opportunity for a personalised intervention at the time the decision is being made.

Keywords

Tissue and Organ Procurement
Registries
Informed consent

Article

Organ transplantation has in many ways been a victim of its own success. The last few decades have seen the indications for transplantation increase, and in virtually all countries' demand for organs far exceeds the number available. Procurement rates remain insufficient due to a number of factors including legislation requiring the use of seat belts and gun control, however even when deceased individuals are able to donate organs, some families refuse consent to donation, while others are never asked.

There is now, however, some reason to believe that it may be possible to increase the conversion rates of potential donors to donors. Early results from the US Organ Donation Breakthrough Collaborative suggest adoption of best practice models from hospitals with the highest donor rates may lead to significant increases in donor rates in participating hospitals(1). The Commonwealth Government is implementing a similar program, investing \$151 million for the "World's Best Practice National Reform Plan for Organ and Tissue Donation for Transplantation"(2). This plan includes a nationally coordinated system for organ and tissue donation, funding for extra staff, and a communication strategy that will encourage family discussion and provide factual information about donation.

The rationale for encouraging family discussion is that consent to donation is considerably higher when the deceased had previously indicated a wish to donate and had discussed this with their family(3). The vast majority of families consent to donation when the deceased had indicated this was their wish, and virtually none override a stated wish not to donate. In contrast, where an individual's wishes are unknown, approximately half of families consent and half refuse(3). It is noteworthy, however, that while there is evidence that education encouraging people to communicate a decision does result in more individuals making a decision, the extra one million registrations on the AODR since 2002 have not actually led to more donors(2). While individuals may be influenced by promotion to discuss their wishes with their family, if concerns about donation are not concurrently addressed there is no guarantee they will affirm in favour of donation(4).

The Australian model for communicating wishes about donation is currently the Australian Organ Donor Register (AODR). By July 2008, 5.5 million Australians had used the register to indicate either consent or intent to donate their organs and tissues,

while only 3438 had registered dissent(5). Those most positive about donation appear most likely to take the time to identify and complete the AODR form.

There are a number of problems with the AODR model. First, it has no mechanism for requiring individuals to make a decision concerning donation on a regular and ongoing basis. Instead, it relies on promotional material encouraging individuals to navigate to a website and fill in the relevant form. Although the AODR matches international benchmarks for the proportion of the adult population that have registered(6), the wishes of two thirds of Australian adults remain unknown. By not capturing donation preferences as part of an existing task, funding is not only required to positively influence donation intentions, but also to encourage action to register those intentions.

The second weakness of the AODR is doubt concerning the validity of consent obtained through a web-based system. While initially the AODR was a register of intent to donate organs and tissues, in 2005 provision was made to also allow individuals to register consent. This is an important shift as the elements of consent, voluntariness, competence, information, understanding and specificity – never easy to ensure even in face-to-face clinical settings – become arguably less valid when healthcare decisions are conducted online. It is noteworthy that a review of the websites of United States Organ Procurement Agencies found that none of them met the information disclosure requirement for informed consent, and that instead content predominantly provided positive reinforcement and promotional information about donation(7).

Third, the AODR does not provide an opportunity for a personalised intervention regarding individual attitudes toward donation. This may be critically important as there is some evidence that public education encouraging individuals to make a decision without personally addressing fears and concerns may lead to more individuals holding a negative rather than positive intention concerning donation(8). In contrast, a personalised intervention with a properly trained individual provides a targeted opportunity to correct specific misunderstandings and may encourage those who are undecided about donation to become donors(9).

An alternative method of registering intent concerning donation in New South Wales (NSW) has been to enable people to indicate their preferences regarding organ donation while renewing their driver's licence at a branch of the licensing authority, the Roads and Traffic Authority (RTA). This method of registering intent may provide a possible solution to the limitations of the AODR by utilising the opportunity for a personalised intervention concerning donation. While this will add a significant burden to the function of licensing agencies and require increases in funding, it may be possible to identify and train staff members about the important medical, legal, socio-cultural, and moral aspects of organ and tissue donation. This model would directly address the identified limitations of the AODR by attaching donation registration to an existing task, and by providing a personalised discussion that would both ensure

informed consent and clarify questions and concerns for individuals unsure about their decision.

Specific strategies could be tailored to each of the possible responses concerning donation. If the question is left blank, discussion could identify whether this was an oversight or whether the individual had particular concerns about donation. An indication of unwillingness to donate could prompt sensitive inquiry to establish whether this was based on factual errors amenable to education and change. And if the individual had indicated yes to donation, this could trigger discussion about the importance of telling one's family, thereby both cementing the decision and potentially encouraging a further well informed discussion with other family members.

One argument presented against the existing NSW RTA model is that the observed rate of donation refusal exceeds the rate expected based on public attitudinal studies(6). However the willingness to express a positive attitude toward a socially approved activity is not the same as a willingness to take concrete action; this is clear in that the apparent high level of public support does not translate into correspondingly high consent rates(10). Values and beliefs about donation are nuanced and holding positive beliefs about the benefits of donation and transplantation are not incompatible with holding competing beliefs that may appear to militate against donation, such as concerns about disfigurement of the body. It must be accepted that some individuals do not wish to donate and a register of non-consent is one way of recognising autonomy in that decision. While it is reasonable to be concerned that some decisions made in the RTA may be time pressured or poorly considered, this should be a sign that more effort is required to ensure individuals are making well-informed decisions; simply failing to record non-consent is an inadequate response to this issue, as such instances should be seen as an opportunity for intervention.

Encouraging individuals to register their wishes concerning donation is the one policy that shows promise in raising consent rates. We should not shy away from the fact that some members of the community do not wish to donate their organs. By engaging in a personal discussion about donation we can both respect the autonomy of the individuals who do not wish to donate, and maximise the opportunity to intervene with individuals who have not made a resolute decision, or who require more information before they do so.

The AODR has no mechanism for requiring individuals to register their wishes, and the online aspect both raises concerns about the validity of consent obtained and precludes personal discussion of fears and concerns about donation. The AODR and similar international online registries are not the ideal systems by which to implement this crucial area of organ and tissue donation policy.

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