
Public education and organ donation: Untested assumptions and unexpected consequences

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While the number of individuals able to benefit from transplantation increases with technological developments, donation rates remain insufficient to cater for demand. A universal response to the insufficient number of donor organs has been public education to increase knowledge about donation and transplantation, and to encourage individuals to register their wishes about donation. Although education appears to have increased knowledge and encouraged individuals to register their wishes, it has not increased the number of organs available for transplantation. In fact, there is some evidence that encouraging people to register their wishes may be detrimental to increasing net donation rates. The failure of education programs to increase organ donation rates may be due in part to a failure to recognise that attitudes to donation are influenced by complex socio-cultural and personal beliefs, and not simply by knowledge. Research aiming to increase the rate at which organs are procured for donation must recognise that some individuals do not support transplantation and have their own personal reasons for maintaining this position. Educational interventions should not assume that increasing knowledge or simply encouraging individuals to declare a decision about donation will increase consent to donation.

INTRODUCTION

Organ transplantation has in many ways been a victim of its own success. Since the first successful live transplant of a cornea in 1905, the indications for transplantation have broadened such that in most countries demand far exceeds the number of organs available. Technological advances continue to increase the number of individuals eligible for transplant while at the same time the number of organs available is falling, due to a number of factors including increased public safety measures, such as legislation requiring the use of seat belts and gun control.

In the context of this disparity, perhaps the issue that has been most prominent in the public and professional discourse has been the fact that people do not choose to donate.¹ Different countries and States have taken various approaches to addressing the shortfall in donated organs, introducing policies for presumed consent, mandated choice and required request; consideration of the use of prisoners' organs; or the creation of a market for the sale of human organs. While different countries have taken different policy approaches to increase donation, all have responded to the poor consent rate by increasing the amount of public education.

Education can be broadly considered as a form of influence. In relation to organ transplantation, education attempts to influence the decision to donate at various stages of the decision-making process, including the public's understanding of organ transplantation, the processes of family decision-making, and the decisions by individuals to donate and to register those decisions in some form. In each case, the goal of public education is to increase the number of organs procured either by increasing intent or declaration of intent to donate one's organs.

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¹ Siminoff LA, Gordon N, Hewlett J and Arnold RM, "Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation" (2001) 286 (1) JAMA 71.

While using public education to increase awareness of the issues surrounding organ transplantation and increase donation appears self-evident, it relies on a number of untested assumptions. This article evaluates the evidence underlying the use of public education in organ donation, investigates the significance of personal beliefs in donation decisions, and considers the implications of these results for the construction of policy to increase organ donation.

PUBLIC EDUCATION IN ORGAN DONATION

There are two broad issues within public education as it relates to organ donation: intention declaration and information provision. Intention declaration refers to the acts of individuals registering their personal decisions about donation in some form. Information provision refers to the presentation of factual information about organ donation, either to reinforce the positive aspects of donation and transplantation or to address concerns surrounding the practice of organ procurement.

The best means for assessing the success of public education programs of either type would be to see if the policies have caused an increase in the consent rate to organ donation. Unfortunately, this is difficult to do with any degree of certainty, as longitudinal records of population consent rates have not been published. Although procurement rates have not increased,² it is difficult to draw conclusions as there are numerous direct and indirect influences on organ procurement.

Intention declaration

Considerable effort has been invested in encouraging individuals to declare their intentions about donation in order to increase consent for organ donation.³ The basis for this are the observations that families rarely override a deceased individual's wish to donate their organs, and that families who do not know the wishes of the deceased are uncertain about whether to consent to donation.⁴ Methods of declaring intention include carrying an organ donor card, signing an organ donation register, or communicating a decision to one's family.

While evidence for an increase in consent rates is lacking, there is some evidence that education encouraging people to make and communicate a decision does result in increased numbers of individuals actually making a donation decision. One study demonstrated a doubling of the number of individuals signing a donor card following an intervention encouraging this behaviour.⁵ A further study provided a static picture of the number of individuals who have made decisions under the influence of a United States campaign that has been running since 1995 to encourage individuals to make an affirmative decision about donation. 47% of the families approached about donation had previously discussed the issue with the deceased, and 71% of the families were aware whether or not there was a donor card (29% knew there was a card and 71% knew there was no card); overall 48% of families felt they knew what the wishes of the deceased were.⁶ It does, therefore, appear that public education aimed at encouraging individuals to make a decision and communicate that decision to their family does have some success in achieving this.

Information provision

While the public is generally supportive of transplantation, there remains a lack of enthusiasm about donation. It is frequently asserted that this is due to a deficit of knowledge about organ donation and transplantation, and therefore what is required is provision of more information. A number of deficits of knowledge have been identified, and it is suggested that if they are corrected there will be an

² Siminoff LA, Arnold RM, Caplan AL, Virnig BA and Seltzer DL, "Public Policy Governing Organ and Tissue Procurement in the United States. Results from the National Organ and Tissue Procurement Study" (1995) 123 (1) *Annals of Internal Medicine* 10.

³ Siminoff LA and Lawrence RH, "Knowing Patients' Preferences about Organ Donation: Does It Make a Difference?" (2002) 53 (4) *J Trauma* 754.

⁴ Siminoff and Lawrence, n 3.

⁵ Sanner MA, Hedman H and Tufveson G, "Evaluation of an Organ-donor-card Campaign in Sweden" (1995) 9 (4) *Clin Transplant* 326.

⁶ Siminoff and Lawrence, n 3.

increase in the consent rate for donation. This includes suggestions to raise awareness of the benefits to recipients, the critical need for organs leading to many people dying on the waiting list, and the fact that transplant programs are by their nature completely dependent on the community supporting something for which they may have no immediate tangible benefit.⁷ A further suggestion is to use public education in order to address concerns surrounding donation, including those about obvious changes to physical appearance, potential costs incurred by the family or delay of the funeral.⁸

As with the strategy of intention declaration, evidence that information provision has increased consent rates is not available. Although there is some indirect evidence that awareness and support for organ donation is increasing over time,⁹ there have been no published serial measurements of knowledge about organ donation. Research has established that the public has deficiencies of factual knowledge about particular aspects of donation and transplantation,¹⁰ and while this correlation between poor factual knowledge and lower rates of donation has been demonstrated, evidence of causation is lacking.

Summary

Public education has been used to increase the number of individuals communicating their personal decision about donation and there is evidence that this has been moderately successful in increasing the number of people declaring their intention in some form. Public education has also been used to overcome perceived deficits of knowledge that are believed to explain the disparity between support for transplantation and lack of enthusiasm for donation, and there is some evidence that over time the public is becoming more knowledgeable about aspects of donation and transplantation. There is no evidence that either of these strategies have increased organ procurement rates, although the large number of factors influencing this rate does not preclude the possibility that public education has had some positive impact.

PERSONAL BELIEFS INFLUENCING ORGAN DONATION

While some concerns about donation involve factual errors that can be dispelled by explanation of the reality of the donation process, some involve personal beliefs that cannot be similarly addressed. These beliefs have been variously described in the literature as mystical thinking, ancient fears and non-rational responses. Such personal beliefs may be important in the context of organ donation as research indicates that families tend to make decisions about donation quickly,¹¹ drawing on their own values and beliefs. Indeed, there is some evidence that an individual's feelings about donation correlate more strongly with intention to donate than does an individual's knowledge of donation, and that people are generally less willing to donate organs they perceive as more sacred, emotional and mysterious.¹² The importance of personal beliefs is further highlighted by the observation that many people explicitly acknowledge they are making a non-rational decision about donation yet remain

⁷ Manninen DL and Evans RW, "Public Attitudes and Behavior Regarding Organ Donation" (1985) 253 (21) *JAMA* 3111; Cantarovich F, "Reducing the Organ Shortage by Education and by Fostering a Sense of Social Responsibility" (2003) 35 (3) *Transplant Proc* 1153; Cantarovich F, "Improvement in Organ Shortage Through Education" (2001) 73 (11) *Transplantation* 1844.

⁸ Siminoff et al, n 1; Hausteil SV and Sellers MT, "Factors Associated with (Un)willingness to Be an Organ Donor: Importance of Public Exposure and Knowledge" (2004) 18 (2) *Clin Transplant* 193; McIntyre P, Barnett MA, Harris RJ, Shanteau J, Skowronski J and Klassen M, "Psychological Factors Influencing Decisions to Donate Organs" (1987) 14 *Adv Cons Research* 331.

⁹ Verble M and Worth J, "The Case Against More Public Education to Promote Organ Donation" (1996) 6 (4) *J Transpl Coord* 200.

¹⁰ Siminoff et al, n 1; Siminoff LA, Burant C and Youngner SJ, "Death and Organ Procurement: Public Beliefs and Attitudes" (2004) 59 (11) *Soc Sci Med* 2325.

¹¹ Siminoff LA, Arnold RM and Hewlett J, "The Process of Organ Donation and Its Effect on Consent" (2001) 15 (1) *Clin Transplant* 39.

¹² Wilms G, Kiefer SW, Shanteau J and McIntyre P, "Knowledge of Image of Body Organs: Impact on Willingness to Donate" (1987) 14 *Adv Cons Research* 338.

comfortable with their decision. This is illustrated in the form of fatalism, where individuals remain reluctant to sign a donor card for fear of encouraging their own death, but nonetheless acknowledge their belief is illogical.¹³

Some large studies have included attitude and belief scales as part of their methods.¹⁴ While these are successful at identifying factors correlating with the decision of whether or not to donate, they do not directly investigate personal beliefs that do appear to play important roles. Three areas of research can be identified that directly investigate personal beliefs surrounding donation.

First, hospital personnel have been surveyed to determine which organs they were least likely to want to donate. The most common reason given for the top four choices was “ancient fears”; this category included fears of dismemberment or mutilation, and fears based upon the need to preserve body parts for another world following death.¹⁵ This research is striking as it suggests that even those most likely to be well-educated and knowledgeable about donation may still hold ancient fears that increase their hesitancy to donate particular organs. In fact, education may even have a paradoxical effect, with one study showing that the specific fear of mutilation in bone donation appears to have been heightened in those organ procurement staff who had actually witnessed the procedure.¹⁶

Second, a source of information about personal beliefs is the reports of organ procurement staff of reasons commonly advanced by families for refusing donation. These reasons include fears that an individual may not be dead, concern that the body should be buried whole, and the belief that a particular body part is associated with the soul or personhood of the deceased.¹⁷

The third source of information about personal beliefs is through interview studies with families who have made a decision about donation. Explanations proposed to account for the influence of personal beliefs in organ donation include the “illusion of the lingering life”, a description of an individual’s inability to imagine their own non-existence, thereby ascribing to the dead body qualities that only a living individual possesses.¹⁸ This may explain discomfort experienced with the thought of cutting a dead body or removing organs in death. A further explanation derived from interviews is the “protection of the value of the individual”, which includes the belief that the dead should be treated with respect to ensure their symbolic survival.¹⁹ This may aid in explaining the discomfort associated with the thought of the deceased being used for spare parts or as a means for another’s wellbeing.

Summary

Personal beliefs appear to be an important factor influencing the decision of whether or not to donate. The limited research in this area has investigated the view of organ procurement staff, the views of families as reported by donation coordinators, and interviews of families who have made a decision about donation. There is evidence that individuals remain comfortable with behaviours they identify as non-rational, and hospital personnel – those most likely to be educated about donation – identify ancient fears as the most influential reasons for not wanting to donate particular organs. There is also evidence that some individuals feel a need to maintain bodily integrity after death, and that organ donation may disrespect the memory of the deceased through mutilation of the physical body.

¹³ Corlett S, “Public Attitudes Toward Human Organ Donation” (1985) 17 (6 Suppl 3) *Transplant Proc* 103; Sanner M, “A Comparison of Public Attitudes Toward Autopsy, Organ Donation, and Anatomic Dissection. A Swedish Survey” (1994) 271 (4) *JAMA* 284.

¹⁴ Siminoff et al, n 1; Siminoff et al, n 11; DeJong W, Franz HG, Wolfe SM, Nathan H, Payne D, Reitsma W et al, “Requesting Organ Donation: An Interview Study of Donor and Non-donor Families” (1998) 7 (1) *Am J Crit Care* 13.

¹⁵ Verble M and Worth J, “Biases Among Hospital Personnel Concerning Donation of Specific Organs and Tissues: Implications for the Donation Discussion and Education” (1997) 7 (2) *J Transpl Coord* 72.

¹⁶ Verble M and Worth J, “Reservations and Preferences Among Procurement Professionals Concerning the Donation of Specific Organs and Tissues” (1997) 7 (3) *J Transpl Coord* 111.

¹⁷ Verble M and Worth J, “Fears and Concerns Expressed by Families in the Donation Discussion” (2000) 10 (1) *Prog Trans* 48.

¹⁸ Sanner M, “Attitudes Toward Organ Donation and Transplantation. A Model for Understanding Reactions to Medical Procedures After Death” (1994) 38 (8) *Soc Sci Med* 1141.

¹⁹ Sanner, n 18.

DISCUSSION

Scientists, health professionals and policy-makers frequently have difficulty understanding why members of the general public are not as enthusiastic as they are about the possibilities that science or technology may offer. One explanation that they often provide is that the public is deficient in knowledge about science and technology, and that if they were more informed they would be more supportive of the processes and products of science and technology.²⁰ This is termed the “deficit model” of science. While this model has generally been applied to science, it has considerable relevance to the development of public policy designed to increase donation rates; it has underpinned research on organ donation which has tended to conclude that the public lacks knowledge about organ donation and transplantation and that donor rates would be increased by public education programs.

Three topic areas within organ donation and transplantation have been suggested upon which the general public requires further education. The first is education to increase awareness and support for transplantation and to correct factual errors concerning the donation process. However, education to raise support and awareness appears unnecessary as the public is both aware of the need for donated organs and supportive of the practice of transplantation.²¹ Further, education about factual errors concerning the donation process may be superfluous as organ and corneal procurement staff report that within the donation discussion they find it relatively easy to address particular concerns, including those of obvious changes to physical appearance, potential costs incurred by the family, and delay of the funeral.²²

The second area suggested for public education is to influence and overcome those personal beliefs that negatively influence organ donation;²³ however, there is currently no evidence to suggest that this is possible. In fact, an examination of the rituals surrounding death, such as choosing burial clothes for the deceased, suggest that issues surrounding death are heartfelt and illogical rather than rational or intellectualised.²⁴ Individuals see their bodies as sacred and integral to their identities, and organ donation must be seen from these perspectives in order to understand the personal responses involved.²⁵ Importantly, while it has not been established that personal beliefs can be directly negated by education, there is some evidence that these beliefs can be counterbalanced by rational arguments and presentation of factual information about donation and transplantation.²⁶

The third area of public education use has been to encourage people to declare their intention to donate, and there is evidence that more individuals have indicated a decision about donation. This strategy will increase donation rates among individuals who state their intention to donate, but it will also decrease donation rates for those who state their intention not to donate. For this policy to succeed, it is crucial that more people declare that they want to donate than explicitly declare that they do not want to donate.

The assumption that more people will declare an intention to donate rather than not donate is based on questionnaires showing that a significant part of the general public state they are willing to

²⁰ Irwin A and Michael M, *Science, Social Theory and Public Knowledge* (Open University Press, 2003).

²¹ Manninen and Evans, n 7; McIntyre et al, n 8; Evans RW and Manninen DL, “US Public Opinion Concerning the Procurement and Distribution of Donor Organs” (1988) 20 (5) *Transplant Proc* 781; Organization TG, *The American Public’s Attitudes Toward Organ Donation and Transplantation* (Partnership for Organ Donation Inc, Boston, 1993).

²² Siminoff et al, n 11; Verble and Worth, n 17.

²³ Siminoff et al, n 1; Cantarovich, n 7 (2003); Cantarovich F, “Public Opinion and Organ Donation Suggestions for Overcoming Barriers” (2005) 10 (1) *Ann Transplant* 22.

²⁴ Verble and Worth, n 9.

²⁵ Belk RW, “Me and Thee Vs Mine and Thine: How Perceptions of the Body Influence Organ Donation and Transplantation” in Shanteau J and Harris RJ (eds), *Organ Donation and Transplantation: Psychological and Behavioural Factors* (American Psychological Association, 1990) pp 139-149.

²⁶ Sanner, n 18.

donate, and some are also willing to talk to their family about their decision.²⁷ However, the disparity between the relatively high level of support for transplantation and the significantly lower rates of donation²⁸ suggests that stated intention to donate is a poor predictor of true intention, or willingness to donate at all.²⁹ Surveys investigate attitudes in a context quite different from that in which decisions and discussion about donation are made and may be affected by a desire to provide a socially approved response.³⁰ This suggests that results of “willingness to donate” surveys should be interpreted conservatively. This does not appear to have been the case of the largest study of willingness to donate, where the category “willing to donate” included both individuals “very willing to donate” (37%), as well as the more equivocal group, those “somewhat willing to donate” (32%).³¹ Of the other 25% of respondents who stated they were not willing to donate, three-quarters had not discussed their preferences with their family, and one-quarter were very willing to do so.³² This demonstrates that a sizeable minority of respondents were against organ donation, and significantly fewer of these had discussed this with their family compared with those willing to donate. This indirect evidence is not conclusive in establishing that, when encouraged to make a decision, more people will state their intention to donate their organs rather than refuse to donate them.

Australian data provide some of the limited direct evidence of how individuals respond to a campaign to increase the number of individuals making a donation decision. As in the United States, public education on organ donation in Australia has directed resources toward encouraging the general public to tell their families about their wishes regarding donation. The 4.4 million driver’s licence holders in Australia’s most populous State, New South Wales, can indicate their organ donation preferences on their licence as “yes”, “no”, “not stated”, or specify particular organs they wish to donate. Over the period from 1997 to 2004, the percentage of licence holders in the “not stated” category fell from 40.6% to 21.4%. This suggests that the effort to encourage people to make a decision was successful. Over the same period, the number of those indicating “yes” to donation rose by 17.7% (from 35.6% to 41.9%); however, the ratio of those indicating “no” rose by 57.8% (from 19.9% to 31.4%). People have moved from the “not stated” category to the “no” category at two times the rate at which they have moved to the “yes” category.³³ Some recent evidence is also available from the United States where respondents indicated that while only 18% were undecided about their donation registration status, almost 50% of respondents declared their intention *not* to donate their organs.³⁴ As families almost never override any suggestion that an individual was unwilling to donate, it appears that this policy may be having the effect of ensuring that many families no longer even consider the possibility of consenting to donation.

This relatively large increase in intention not to donate organs may reflect well-informed and enduring expressions about organ donation. Alternatively, it has been suggested that a lack of associated personalised discussion of fears and concerns when making a decision may increase

²⁷ Organization TG, n 21; Guadagnoli E, Christiansen CL, DeJong W, McNamara P, Beasley C, Christiansen E et al, “The Public’s Willingness to Discuss Their Preference for Organ Donation with Family Members” (1999) 13 (4) *Clin Transplant* 342.

²⁸ Siminoff et al, n 11; Organization TG, n 21.

²⁹ Prottas JM, “Encouraging Altruism: Public Attitudes and the Marketing of Organ Donation” (1983) 61 (2) *Milbank Memorial Fund Quarterly Health and Society* 278.

³⁰ Barnett MA, Klassen M, McMinimy V and Schwarz L, “The Role of Self- and Other-oriented Motivation in the Organ Donation Decision” (1987) 14 *Adv Cons Research* 335.

³¹ Organization TG, n 21.

³² Guadagnoli et al, n 27.

³³ New South Wales, Roads and Traffic Authority, *Vehicle Licensing and Organ Donation Statistics* (RTA, 1997-2004), <http://www.rta.nsw.gov.au/publicationsstatisticsforms/downloads> viewed 30 October 2005.

³⁴ Rodrigue JR, Cornell DL, Jackson SI, Kanasky W, Marhefka S and Reed AI, “Are Organ Donation Attitudes and Beliefs, Empathy, and Life Orientation Related to Donor Registration Status?” (2004) 14 (1) *Prog Trans* 56.

refusals,³⁵ and there is evidence that, when such a discussion does take place, more of those initially undecided will make an affirmative decision about donation as opposed to a negative one.³⁶

CONCLUSIONS

Public education encouraging people to register their decision in some form appears to have had some success. Unfortunately, there is evidence those who have been encouraged to register a decision may indicate a desire *not* to donate at a rate higher than they are indicating a desire to donate. Well-informed decisions about donation preferences are an effective method of ensuring a deceased individual's wishes are respected. However, encouraging intention declaration without an associated personalised discussion of fears and concerns appears to be a policy that is unlikely to increase donation rates; in fact, it may decrease them.

To engage the public and encourage trust in the system of organ donation, there is a need to acknowledge that the public holds complex and nuanced views about donation.³⁷ When investigating the role of personal beliefs in organ donation, it is imperative that the issue is not again constructed purely in terms of a deficit of knowledge. Instead, research should aim to more closely examine the nature and role of personal beliefs influencing the decision by families to donate, and more importantly, not to donate. This research must engage the public in discussion, free of any agenda to raise donation rates. Only when this poorly charted area is better understood can a decision be made about whether these personal beliefs are amenable to change, and if so, by what means.

³⁵ Siminoff et al, n 2; Chouhan P and Draper H, "Modified Mandated Choice for Organ Procurement" (2003) 29 J Med Ethics 157.

³⁶ Sanner, n 18; Stevens M, "Factors Influencing Decisions About Donation of the Brain for Research Purposes" (1998) 27 (5) *Age Ageing* 623.

³⁷ Irwin and Michael, n 20.