

David Shaw
Bernice Elger

Persuading bereaved families to permit organ donation

Received: 21 August 2013
Accepted: 30 August 2013
Published online: 27 September 2013
© Springer-Verlag Berlin Heidelberg and ESICM 2013

D. Shaw (✉) · B. Elger
Institute for Biomedical Ethics, University of Basel,
Bernoulistrasse 28, 4056 Basel, Switzerland
e-mail: david.shaw@unibas.ch
Tel.: +44-7-790141063

Introduction

The annual UK potential donor audit captures families' reasons for not consenting to donation of their deceased family members' organs [1]. Given that many families' refusals and vetoes are based on false beliefs, cognitive bias and misunderstanding, it is incumbent upon doctors, nurses and transplant coordinators to invest sufficient time to facilitate informed consent or authorization. While such families are distressed, organ donation rates could be substantially improved if they were made aware of any mistaken beliefs, using recently suggested criteria for the ethical use of persuasion [2]. This article examines some of the reasons for refusal of donation and suggests ways to help families make better decisions. It emerges that the use of persuasion is ethically essential in order to prevent families making decisions that they may come to regret.

Persuading bereaved families

In the UK in the year up to March 2012, 2,143 people died and donated their organs, resulting in a total of 3,960

transplants [3]. An average of three potential organ donors per day did not have their organs taken because of family refusal. The number of people dying each day while waiting for an organ could be halved if all these families could have been persuaded to permit donation. Some healthcare professionals claim that it is unethical to attempt to influence families' decisions about donation in any way; such families are in a state of extreme emotional distress and attempting to persuade them to donate their loved one's organs could make them feel even worse. However, there are three reasons to attempt to persuade them [4]. First, several people will die or experience greater suffering if the organs are not donated. Second, in many cases, the deceased will be on the organ donor register, and their wishes should be respected. Third, most families come to regret refusing to allow donation, whether or not the deceased was on the register [5]. For all of these reasons, families should be persuaded to permit donation. In Box 1, we provide an adapted list of criteria to ensure that families of potential donors are treated with respect when persuasion is used.

Box 1 Criteria for ethical persuasion of families

- (1) Remove cognitive and informational biases and access the family's wishes
- (2) Provide honest, impartial evidence-based information about organ transplantation and its benefits, and the wishes of the deceased
- (3) Provide a rational interpretation of this information, including facts about the professional's belief-set and views regarding the best decision
- (4) Use reason rather than emotion, while sometimes appealing to the family's emotions to counterbalance their existing emotional responses
- (5) Avoid creating new biases
- (6) Be sensitive to the family's changing preferences, as persuasion is likely to change their outlook and perspectives^a

^a Adapted from Shaw and Elger [2]

Table 1 Reasons for refusing donation and suggestions for addressing them

Reason	Suggestion
Patient had stated in the past that they did not wish to be a donor	Tell the family that if the deceased was on the register his/her wishes should be respected
Family were not sure whether the patient would have agreed to donation	Ask the family if the deceased would have wanted to save a live and improve three others
Family did not want surgery to the body	Remind the family that the decision should be based on the patient's rather than the family's viewpoint
Family felt it was against their religious/cultural beliefs	Ask the family whether it would be against the deceased's beliefs
Family were divided over the decision	If the donor's wish was to donate, the default should be to donate organs

Providing the family with information is obviously essential in order to remove misunderstandings about brain death and other issues. If a family refuses to donate because they believe that saving one person's life is not worth mutilating the body of the deceased, they should be told that several lives could be saved and many improved by donation. This might not seem like persuasion, but the provision of accurate evidence in order to correct a false belief and change the resulting action is exactly that. Furthermore, families in this situation are affected by massive cognitive bias due to their extreme distress (and would quite probably not meet the standards for informed consent if they were being asked to consent to an operation for themselves). They understandably do not want to "lose" any more of their relative than they already have, and as such are affected by a short-term bias in their thinking. Consequently, the idea that they might come to regret vetoing donation is unlikely to occur to them without intervention.

Addressing reasons for refusal

The best way to persuade families to permit donation is to address their reasons for refusing to give permission. The UK annual organ audit also captures these reasons. In this section, the five most common reasons are analyzed, and suggestions are provided regarding how to sensitively address families' concerns. These reasons and suggestions are also summarized in Table 1.

Patient had stated in the past that they did not wish to be a donor

If the deceased was on the donor register, the family should be told this and reminded that the deceased's wishes must be respected, unless the family claims that this wish was changed since the person signed up for the register. If the deceased was not on the register and there was sufficient time, it might be helpful to contact the

patient's general practitioner (GP) to check whether he/she has discussed organ donation with the patient and documented patient agreement. This shows that GPs could play an important role if they systematically discussed organ donation with their patients. However, if there is no evidence that the person had changed their intentions, the refusal must be respected.

Family were not sure whether the patient would have agreed to donation

If the donor was on the register or had talked to his/her treating physician, this question is answered; if not, it might be helpful to ask the family if the deceased would have wanted to save a live and improve three others. This objection might also be easier to overcome under a presumed consent system, where anyone who did not want to donate should have declared it.

Family did not want surgery to the body

Once again, if the deceased was an organ donor that choice should override family concerns; otherwise, it should be discussed with the family whether the refusal of surgery was the patient's genuine wish or the preference of the family and that the decision should be based on the patient's rather than the family's viewpoint. In addition, it could be pointed out to the family that another family elsewhere will probably lose a loved one if they do not give their consent.

Family felt it was against their religious/cultural beliefs

The family should be asked whether it would be against the deceased's beliefs. If not, doctors should explain that the donor's wishes have precedence [6] and that donation should therefore proceed. Another possibility is to mention that many religions would regard it as a good deed to save others' lives.

Family were divided over the decision

It is important to understand whether family members disagree about the presumed wish of the donor or whether the disagreement represents the distinct opinions of family members themselves. Refusing to donate is making a decision; if the donor's wish was to donate, the default should be to donate organs, even if there is disagreement within the family. Consent is only required from one family member, and families could be (truthfully) told that some families never reconcile because donation was stopped by one dissenting relative.

Conclusion

Used properly, persuasion can be a supportive mechanism, allowing families to be counseled objectively without crossing the line into unethical coercion. It is entirely ethical to attempt to persuade families to permit donation, and in many cases doing so is essential in order

to respect not only the patients' but also the family's autonomy. Above all, families asked to make this decision should be given the information relevant to their decision: if the deceased was a registered donor, the family must be told this. If families are unaware of the potential benefits flowing from donation, they should be told about them. If they offer weak reasons, they should be persuaded of the problems with such reasons. And last but not least, they should be informed that many families who refuse consent ultimately come to regret doing so. It has been suggested that families' decisions regarding donation should not be challenged as they are very distressed due to the loss of a loved one, but to further handicap their capacity for decision-making by withholding key information is to disrespect them more than giving into their refusal. Although families are not patients, they have a right to receive the relevant information, and pointing out flaws in their beliefs and reasons via the process of benign persuasion is essential.

Conflicts of interest None.

References

1. NHS Organ Donation (2012) Potential donor audit summary report for the 12-month period 1 April 2011–31 March 2012. Available at: http://www.organdonation.nhs.uk/statistics/potential_donor_audit/pdf/pda_report_1112.pdf. Accessed 15 Aug 2013
2. Shaw D, Elger B (2013) Evidence-based persuasion: an ethical imperative. *JAMA* 309(16):1689–1690
3. NHS Organ Donation (2013) Statistics. Available at: <http://www.organdonation.nhs.uk/statistics/>. Accessed 15 Aug 2013
4. Shaw D (2012) We should not let families stop organ donation from their dead relatives. *BMJ* 345:e5275
5. Morais M, da Silva RC, Duca WJ (2012) Families who previously refused organ donation would agree to donate in a new situation: a cross-sectional study. *Transpl Proc* 44(8):2268–2271
6. Human Tissue Authority (2006) Code of practice 2: donation of solid organs for transplantation. Available at: www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm. Accessed 15 Aug 2013