Organ donation: the debate

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Rosie Wilkinson BSc, RGN, OND, RNT, Cert Ed, Dip Ethics, is an Adviser in Nursing Practice, Royal College of Nursing.

Summary

A resolution due to be debated at the RCN's annual congress in Bournemouth next week will ask members to 'urge the government to introduce an opt-out system of organ donation' (RCN 2000). This article highlights some of the key issues. A questionnaire appears with this article and we would like to hear your views

Introduction

In the United Kingdom the current system for obtaining organs from cadavers is one that requires 'opting in'. There is increasing concern that this system is failing to meet the demand for organs suitable for transplantation. More than 5,000 people in the UK are waiting for an organ transplant and approximately 2,800 organs are transplanted each year (UKTSSA 1999). Recently, there has been a move to lobby for a change in legislation and the introduction of a system of 'presumed consent'. Polls suggest that 70 per cent of individuals would be willing to donate their organs after death, but only 20 per cent make their views known by carrying a donor card (Payne 1994).

In 1993, the RCN favoured an 'opt-in' system, allied to improvements in education and public awareness of the need for donation. When considering organ transplantation, ethical and philosophical issues cannot be ignored and the debate needs to focus on questions such as:

- Who owns the body of the deceased?
- How do cultural background and public opinion influence perception?
- Is it right to override the next of kin's position on the subject?

The BMA, at its 1999 annual meeting, passed a resolution to lobby the government to introduce a system of 'presumed consent' for organ donation (Beecham 1999). It is currently seeking views on a consolidated approach to the many issues involved. The British Transplant Society and the UK Transplant Co-ordinators Society have held a referendum to ascertain their members' views, and similarly, the RCN would like to identify the views of its members.

Opting out – opting in

Opting out is a system where organs may be removed after death, unless individuals state during their lifetime that this is not their wish. This system is also referred to as 'presumed consent', as it is based on the assumption that silence or inaction implies consent. This is the opposite of the current system, where donors or their relatives must state their wishes before donation can proceed. Currently, individuals can indicate their wishes in a number of ways – by signing donor cards, recording their name on the NHS Organ Donor Register, or by making sure that their relatives and those closest to them know of their wishes.

The legislation

The Human Tissue Act 1961 (covering England, Wales and Scotland) and the Human Tissue Act 1962 govern the removal of organs from people after death in the UK (cadaveric donors).

The Human Tissue Act describes the circumstances in which organs may be removed. A designated person may authorise removal of organs once enquiries have been made to ensure that there is no reason to believe that:

- The deceased had expressed an objection to his or her body being dealt with in this way after death and had not withdrawn it.
- The surviving spouse, partner or any relative of the deceased, objects to the body being so dealt with.
- There are religious objections.

If an inquest is to be held, a coroner might request a post mortem and the Act states that organs or tissues may only be removed with the specific authorisation of the coroner or procurator fiscal in Scotland.

There is confusion about 'lawful ownership of the body' and about making 'such reasonable enquiry as may be practicable' – usually a pragmatic approach is taken. The standard practice is to seek the consent of relatives, even though the legislation only requires that the person lawfully in charge of the body has made enquiries to ensure that the relatives have no objection to the donation.

The Human Organ Transplant Act was introduced in 1989. It prohibits the sale of human organs and stipulates that living organ donors are genetically related to the recipient. Unrelated live donation can take place if the Unrelated Live Transplant Authority (ULTRA) approves the case.

If there is to be a change in legislation, consideration needs to be given to the type of law made. A rigid or 'hard' law, which allows relatives no input into the donation process, has been shown to be unsuccessful in France and elsewhere. A 'soft' law, where relatives are allowed to veto donation if they are aware of an unregistered dissent or have strong personal feelings, appears to work well in countries such as Belgium. It could be argued that if relatives were allowed a power of veto, this would maintain the status quo.

key words

- Transplantation: donation
- Ethics

These key words are based on the subject headings from the British Nursing Index.

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Would you like to contribute to the debate?

Complete the questionnaire on the *Nursing Standard* website www.nursing-standard.co.uk

Further information

The NHS Organ Donor Register
PO Box 14
FREEPOST
Patchway
Bristol
BS34 8ZZ

Arguments for a change in legislation

Surveys carried out by the Department of Health and the British Kidney Patients Association reported by the King's Fund (New *et al* 1994) were in favour of a move to 'presumed consent'. The experience of the Belgium system ten years on has shown a sustained increase in organ donation rates (Michielson 1996).

The current donor card system has not worked as well as anticipated, despite many publicity campaigns. Relatives and family members are still consulted and have the power of veto over the expressed wishes of the donor card holder. Estimates about the increased number of organs that a change in legislation would make available vary between 10 and 50 per cent.

Presumed consent would make donation routine, encourage individuals to make a decision for themselves and minimise the emotional burden on relatives by limiting any inquiries to objections.

Arguments against presumed consent

Many of those who argue against the notion of presumed consent do so because they believe it overrides the important concepts of personal autonomy and the basic human rights of the individual to self-determination.

Those who talk about organ donation also refer to the concepts of 'altruism' and 'gift giving' that would be lost if there were a change in legislation. In addition, legislative changes might attract bad publicity or media hostility, which in turn could affect opt-out rates and the general public's approval of the current system.

A change in the system could provide more organs in the short term, but in the longer term there might be a detrimental effect as patients lose trust in healthcare professionals: '...upon which acts of healing depend' (Veatch 1991).

While some literature suggests that the majority of individuals are not averse to organ donation (Payne 1994), silence, or the fact that there has not been a positive indication of an individual's wishes, may merely be an indication of ambivalence. To assume that this can be interpreted as a desire to donate organs has been described as 'presumptuous and disrespectful' and 'a classic non-sequitur' (Webster 1998).

Ethical principles

Ethical arguments about presumed consent tend to fall into two main groups. On the one hand is the principle of autonomy and the rights of an individual to self-determination, on the other, this has to be balanced against the concerns of utilitarianism – that the greatest good should be done for the greatest number.

When considering autonomy and self-determination, there is a recognition that an individual has authority over his or her own body. Given that respect for individuals is regarded as a crucial moral principle, to weaken an individual's power of direction – even if that direction is after death – is seen by some as an attack on that principle. This raises the question of whether a person who has died is still owed any respect in terms of autonomy, as he or she ceases to be a person after death. Veatch (1991) argues that: '...respect for the individual is a cornerstone in medical ethics and the power to direct some events persists even after death'.

Those favouring a utilitarian argument start from the premise that measures to increase the supply of organs for those who need them is a good thing (Kennedy *et al* 1998).

Other considerations

Should donor cards be considered in the same way as an advanced directive? Should relatives be able to override the expressed wishes of the person concerned? Donor cards are only of benefit if they are available when needed, or if relatives know of their existence and inform the relevant health professionals. Attention needs to be given to the NHS Donor Organ Register to ensure that it is effectively managed and consulted.

Reviewing the funding and support of a national service would help to ensure uniformity and standards, and would create a more structured and directional approach to increasing organ donation rates. This would tie in with the anticipated changes and recommendations made following the Department of Health's review of the UK Transplant Support Services Authority (DoH 2000).

It has been suggested that the new transplant service will focus on increasing the number of ICU beds, training more consultant surgeons and employing more transplant co-ordinaotrs. A centrally controlled and expanded transplant co-ordinator network in Spain has been associated with an increse in the donor rate from five to 31 donors per million since 1985, the highest rate in e Europe. (Jefferey 2000) One option would be to consider a system of 'required referral'; 26 US states have this type of policy (New *et al* 1994). This would mean that any death that occurs in an intensive care unit is referred to an organisation responsible for organ donation and a potential organ donation assessment would be made. As many as 30 per cent of possible donors are not even referred to co-ordinators and their relatives are not approached about donation.

The mandated choice option would require all adults to express their written preference or objection to organ donation. The success of this strategy would still be dependent on an informed and educated public regarding the purpose and importance of organ donation.

Elective Ventilation is a manoeuvre whereby selected deeply comatose patients who close to death, are transferred to the ICU and put on a ventilator to preserve organs for retrieval at death which is likely to occur in a period of hours. This would require the consent of next-of-kin. This

procedure was undertaken by pioneering units in the UK, but, in 1994, the Department of Health deemed it illegal on the grounds that the process was not primarily intended for the patient's benefit, this being a common law requirement in medicine.

Organs may be retrieved from non heart beating donors, here organs are taken from individuals who have died and whose hearts have stopped beating. There is a short period of time during which organs remain viable. Donation is requested from the family. A small number of centres in the UK undertake this procedure and there is more experience in the Netherlands.

Living organ donation applies principally to kidneys but there is some experience with liver sections and lobes of lung. Living related donation, for instance from parent to child or sibling to sibling, produces significantly better kidney survival than caderveric donation. There is also growing experience in unrelated kidney donation, usually spousal, which also produces good results. Living donation is increasing in the UK; between 1992 and 1998 it rose from 5 to 14 per cent of total renal activity. However in the USA it accounts in excess of 30 per cent, of transplants, and more than 50 per cent of activity ion Norway.

Xenotransplantation refers to transplantation of organs across species. Most research has focussed on the genetically engineered pig organs. At present human trials have not started because of immunological rejection, fears about virus transmission, and uncertainty over ethical principles involved.

Conclusion

Long ago, societies realised that it is not possible to rely on the charity of individuals to support its weaker members and the result has been compulsory giving in the form of taxation. Should it be presumed that we give our bodies when death is pronounced? Whatever benefits organ transplantation can provide, the procurement and allocation of organs should proceed a0ccording to principles of equity, public consent and policies that maintain dignity for the human body