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Organ transplantation: approaching the donor's family

Train doctors to approach families sensitively

In 1993, 2970 patients in need of organs were added to the list of those awaiting transplantation.[1] These included 1819 patients awaiting kidneys. While these waiting lists lengthen, however, the availability of donors continues to fall. There is therefore an urgent need to increase the number of donors for organ transplantation.[2-4]

To achieve this end a variety of different strategies has been suggested. For example, some European countries, such as Austria, have legislation that permits doctors to remove the organs of potential cadaveric donors unless they have previously registered their wish to the contrary.[5] The introduction of such legislation in the United Kingdom is advocated by the British Kidney Patients' Association. In certain states in the United States doctors are required to approach relatives of potential donors who are brainstem dead. In the United Kingdom the government has recently set up a transplant register and invited members of the public to register their willingness to become organ donors.

Several studies have pursued the reasons for the lack of availability of organs from cadaveric donors.[6-9] One crucial issue is the refusal of families to give permission for organ donation. This has been highlighted by Gore and colleagues, who estimated that about 30% of relatives of potential brainstem dead donors receiving intensive care refuse to give such consent.[7,8] The figure is considerably higher for some organs, such as heart, liver, and lungs.[8] There is a further loss of up to 10% of cases as a result of staff in intensive care units not approaching families after brainstem death.[7] Furthermore, most families of potential donors cared for in general wards are not approached at all.[9]

One issue that has not been prominent in the debate is the quality of the communication with the family when doctors ask about cadaveric organ donation. This is, of course, an extremely difficult task. Medical staff need to address members of the family while they are facing the death of a father, mother, sister, brother, or child and ask for consent to organ donation. This ordeal was identified by the royal colleges' working party document on the supply of donor organs for transplantation,[10] and the lack of medical experience and knowledge about how to approach relatives was emphasised.

The importance of these issues is confirmed by two recent studies that describe doctors' reluctance to approach grieving families about organ donation for fear of distressing them further.[11,12] In Canada Robinette *et al* reported that half of doctors and nurses expressed reluctance.[11] In the United Kingdom Wakeford and Stepney found that among intensive care units the three most important factors restricting the requests about organ donation were, in order of importance, disquiet about adding to a relative's distress, the lack of training in approaching relatives, and adverse publicity in the media.[12] Furthermore, a survey of house officers showed that three quarters thought that they had inadequate guidance on any form of "breaking bad news."[13]

However, very little empirical research exists on which to base a training programme or to guide practice: how to approach family members, what to say to them, and how organ donation may affect the family's feelings and the process of bereavement. We need to know more about the experience and feelings of relatives—not only those who were asked and agreed but those who were asked and refused and those who were never asked at all. Families should be asked their opinion on what it is that health care workers do or say that is helpful and what is unhelpful or hurtful. How would they prefer to have been approached, and what subsequent support would have been welcomed? Do families find being asked about organ donation an extra burden at a difficult time, or can it in fact be helpful, as some preliminary evidence suggests?[14] The answers may depend critically on how the question is put.

There have been a few rays of light. One study from the United States has provided some simple and helpful pointers on approaching relatives.[15] In particular, relatives were more likely to agree to donation if the explanation of brainstem death and the request for organ donation were clearly separated in time. In the United Kingdom the transplant coordinators have been conducting a questionnaire survey of doctors' perceptions of why relatives refuse consent to donate organs (P E Buckley, personal communication). Most recently, the Department of Health has planned to evaluate a Dutch one day workshop aimed at enhancing the skills of staff of intensive care units in asking relatives about organ donation.

Base training on research

We believe that organ donation is likely to be greatly facilitated if priority is given to ensuring high quality communication between staff and the families of potential donors. This can be achieved only if continuing support and training programmes are firmly based on a body of empirical research. As well as increasing organ donation, such training

should increase the skills and confidence of health care professionals. Furthermore, it should ensure that families are treated with sensitivity and supported whether or not permission for organ donation is given.

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1 UK Transplant Support Service Authority. *Annual Report 1993/94*. Bristol: UKTSSA, 1994.
2 Chisholm GD. Time to end softly softly approach on harvesting organs for transplantation. *BMJ* 1988;**296**:1419-20.
3 Wallwork J. Organs for transplantation. *BMJ* 1989;**299**:1291-2.
4 Organ donors in the UK: getting the numbers right 'ditorial. *Lancet* 1990;**335**:80-2.
5 Land W, Cohen B. Postmortem and living organ donation in Europe: transplant laws and activities. *Transplant Proc* 1992;**24**:2165-7.
6 Gore SM, Hinds CJ, Rutherford AJ. Organ donation from intensive care units in England. *BMJ* 1989;**299**:1193-7.
7 Gore SM, Ross RM, Wallwork J. Availability of transplantable organs from brain stem dead donors in intensive care units. *BMJ* 1991;**302**:149-53.
8 Gore SM, Cable DJ, Holland AJ. Organ donation from intensive care units in England and Wales: two year confidential audit of deaths in intensive care. BMJ 1992;**304**:349-55.
9 Feest TG, Riad HW, Collins CH, Goldby MGS, Nicholls AJ, Hamad SN. Protocol for increasing organ donation after cerebrovascular deaths in a district general hospital. *Lancet* 1990;**335**: 1133-5.
10 Conference of Medical Royal Colleges and their Faculties in the UK. *Report of the working party on the supply of donor organs for transplantation*. London: HMSO, 1987.
11 Robinette MA, Marshall WJS, Arbus GS, Beal K, Bennett RC, Brady WJ, *et al.* The donation process. *Transplant Proc* 1985;**17**(suppl 3):45-65.
12 Wakeford RE, Stepney R. Obstacles to organ donation. *Br J Surg* 1989;**76**:435-9.
13 Dent THS, Gilliard JH, Aarons EJ, Crimlish HL, Smyth-Pigott PJ. Preregistration house officers in the four Thames regions. I. Survey of education and workload. *BMJ* 1990;**300**:713-5.
14 Buckley PE. The delicate question of the donor family. *Transplant Proc* 1989;**21**:1411-2.
15 Garrison RN, Bentley FR, Raque GH, Polk HC, Sladek LC, Evanisko MJ, *et al.* There is an answer to the shortage of organ donors. *Surg Gynecol Obstet* 1991;**173**:391-6.

The future of fundholding

Voluntary for general practitioners, compulsory for health authorities

Ever since the inception of general practice fundholding in 1991 ministers have insisted that it is a voluntary scheme. This approach has resulted in a rapid expansion of fundholding: the proportion of England's population covered by the scheme increased from 7% in 1991-2 to 40% in 1995-6. Population coverage varies widely among districts, however, ranging from 4% to 87% in England in 1994-5.

The announcement last October of an extension to the fundholding scheme marks a further phase in its development.[1] Health ministers clearly think that fundholding is a success and are treating it as the jewel in the crown of the NHS reforms. Independent commentators are more sceptical, arguing that no comparison has been made of fundholding and non-fundholding practices and calling for research into the effects of different models of commissioning health care.[2]

Ministers have gone some way towards heeding this call in deciding that total purchasing by fundholders (purchasing of all health care including maternity, accident and emergency, and medical and psychiatric inpatient services) will be evaluated. It will be compared, however, with the standard, more limited type of fundholding and not with approaches based on commissioning by health authorities. As a result, the government has missed an opportunity to establish the costs as well as the benefits of alternative approaches.

This lack of comparative research reflects the government's view of fundholding as the preferred model of purchasing. Despite assurances last autumn that fundholding would remain voluntary, chairpeople and members of health authorities have been told by ministers and civil servants that their performance will be assessed in terms of the number of practices that can be persuaded to enter the scheme. Put another way, fundholding may be voluntary for general practitioners but is now compulsory for health authorities. The clear implication is that heads will roll if the government's targets for extending fundholding are not met.

There are several risks in this approach. To begin with, one of the reasons why general practitioners have chosen not to become fundholders is that some district health authorities have involved them in commissioning and achieved many of the benefits of fundholding without requiring them to hold budgets themselves. Thus in these districts general practitioners have little incentive to apply to become fundholders. Paradoxically, the more effectively a health authority purchases care directly the more heavily it may be penalised. Fundholding will increase substantially only if health authorities abandon these different approaches and fail to take into account the views of general practitioners. Thus the emphasis now placed on fundholding could be counterproductive and make building on the achievements of health authority purchasers more difficult.[3]

A second risk is that forcing general practitioners into fundholding will further accentuate the problem of low morale in general practice. Surveys suggest that fundholders are concerned about the increased workload arising from the scheme and that a considerable proportion would prefer not to be fundholders.[4] Notwithstanding the attractions of fundholding and the improvements for patients that have resulted, doubts linger about general practitioners' willingness to sustain the effort needed in the longer term. Indeed, maintaining the interest of fundholders is a major management problem, and some of those who became fundholders in the early waves are threatening to pull out. Reluctant fundholding is an oxymoron: the scheme depends on dynamism and desire for change. Resentful fundholders would be bad for patients. Ministers should think carefully before pushing harder to expand the scheme.

A third concern is that an extension of fundholding will increase the costs of transactions in the NHS, partly because of the additional management allowances payable to fundholders and partly because of the extra work for NHS trusts in negotiating cost per case contracts with many small purchasers. The administrative costs of fundholding are two to three times as high as those of purchasing by health authorities. Yet the government is responding to public concern about increasing numbers of managers and cutting out unnecessary bureaucracy in the NHS. Fundholding cannot be exempt from this policy. At the very least, we need to know whether the benefits of purchasing based in general practice outweigh the increased costs.

A fourth worry is that not all general practitioners have the skills needed to manage a budget. While management capacity in primary care has increased recently, a large number of practices are not yet ready to take on the responsibility of fundholding. Entrusting budgets to practices