Meeting the challenges of live donation

A joint conference entitled 'Meeting the challenges of live donation' was held by the British Transplantation Society and the Renal Association at the Royal College of Physicians in April 1998.

Dr Douglas Briggs (Western Infirmary, Glasgow), set the scene by pointing out that although every year in the UK more people are waiting for kidney transplants, there has been no parallel increase in the annual number of these operations since 1990. Despite decades of education and efforts aimed at improving cadaveric donation rates, other proper forces such as seat belt and crash helmet legislation have reduced the usual sources of supply of organs for cadaveric transplantation. In the face of increasing need, it becomes legitimate to examine more closely the potential contribution of kidneys from living donors, currently making up less than 10% of all renal transplants.

The experience in the United States

Dr John Pirsch (University of Wisconsin Hospital) presented data from several years' experience at his hospital, where they do an average of 22 live donor transplants (LDTs) per year, and from other centres in the United States. Their experience includes not only the usual parent-to-child transplant, but also transplants from adult child to elderly parent, between spouses and from friends or work colleagues. They have an overall complication rate of up to 5%, with a 0.03% risk of death. This usually occurs in the immediate postoperative period, mainly from pulmonary embolism. There appears to be very little in the way of long-term risk to the physical health of the donor, but about half of the donors experienced short-term financial difficulties as the result of time off work. Since this problem is now recognised, it can be aired at the consent stage and, if appropriate, arrangements for compensation may be made. However, these financial considerations rarely affected the relationship between donor and recipient following donation, and surveys found on balance that donors derived emotional benefit from their altruism.

The experience in the United Kingdom

Mr Ali Bakran (Transplant surgeon, Royal Liverpool University Hospital) had conducted a survey of LDTs in UK renal units during 1997. Although the number of LDTs has risen, fewer than 200 are carried out annually, less than 10% of all kidney transplants. Results tend to be good, with better patient and graft five-year survival than for a first cadaveric renal transplant. (This probably reflects patient selection and the elective nature of the procedure rather than other factors.) The surgery is not without risk for the donor, the most important complications being thromboembolic events, chest infections, pneumothoraces and myocardial infarctions. As in the United States, compensation for the donor is an issue, but as yet consensus on what to do about it has emerged.

Despite the obvious potential of this source of kidneys, the survey found that little use was made of the skills and experience of transplant co-ordinators or independent advocates to counsel potential donors, and despite the potential for ethical difficulties, 73% of units surveyed had no strategic policy on LDTs. Mr Bakran proposed that co-ordinators and counsellors should play a greater role both in the initial approach to potential donors and in subsequent advocacy.

ULTRA

Professor Martin Bobrow, chairman of ULTRA (the Unrelated Living Transplant Regulatory Authority), gave an account of its origins and workings. It was created following the Human Organ Transplant Act (1989) in response to fears about commercial trading of transplantable organs. Its 12 members are appointed by the government and its remit refers only to transplants between unrelated individuals. Living unrelated transplants must be given prior permission by ULTRA, which has to ensure that every part of the regulatory procedure has been followed by the clinicians involved in the proposed transplant, and that consent is of a high quality, ie that appropriate information has been given and understood, without any form of coercion or inducement. When people whose first language is not English are involved, it can prove difficult to ensure that proper communication has taken place. Payment is specifically forbidden but reasonable compensation is allowed. This clearly leaves the nature of consent open to judgement and in practice ULTRA commissions an independent assessment of the quality of consent where necessary.

Professor Bobrow was keen that ULTRA should be viewed as a positive agency, creating the conditions and safeguards under which live organ donation for transplantation becomes an acceptable procedure. It aims to give, without delay, a clear 'yes' or 'no' to requests and to issue guidelines to facilitate the successful outcome of applications. All this said, the system works on a great deal of trust, as there is no inspectorate or specific policing mechanism.

The experience in Switzerland

Professor Gilbert Tiel (Kantonsspital, Basel) reported that a decade ago Switzerland set up its proactive living donor programme when the demand for cadaveric kidneys for transplantation exceeded their supply. In recognition of
fears concerning the long-term consequences for the donor, they set up a comprehensive donor registry with the intention of lifelong follow-up. So far, there is no evidence for any excess long-term risk to the donors. Another purpose of the registry is to monitor trends in the private sector to guard against any commercialisation. In 1997 there were 48 LDTs in Switzerland, which has a population of 7 million. The annual increase in LDTs reflects a policy of raising the issue up to two years before dialysis is likely to become necessary. LDTs may be done before dialysis to minimise disruption of lifestyle, particularly in a person in employment. Having made the initial approach, the next step is a psychological assessment of both donor and recipient by a third party. Three-quarters of donors are women, possibly because the greater prevalence of heart disease in men makes many unsuitable as donors and, since in Switzerland men tend to be the sole earners in a partnership, they are more reluctant to risk their health or take a break from work.

Live renal donation in children

Dr Bob Postlethwaite (Manchester Children’s Hospital) emphasised the issues specific to LDTs in children. As in adults, the rate of cadaveric kidney donations is static and living donation is a sensible option. Almost all LDTs are from young adult parents to their own children and very little unrelated transplantation is done. A quarter of LDTs are pre-emptive, postponing the rigours of dialysis. Parent-to-child donation poses difficulties with the quality of consent by both donor and recipient; they stem from the parent being strongly emotionally involved with, and in authority over, the child. Parents may feel obliged to donate, and children to accept, and both are vulnerable to the persuasive influence of doctors, so a great deal of care must be taken in informing all those involved. One helpful move is to bring in donor support groups at an early stage.

Donor assessment

Professor Michael Nicholson (Leicester General Hospital) covered practicalities of donor assessment. The principles that govern his approach are: first, to protect the donor from harm; second, to ensure as good an outcome as possible for the recipient whilst, third, avoiding unnecessary procedures. Three specific objectives flow from these principles: to identify contraindications early, to identify and avoid unreasonable risks and to obtain good quality of consent. These objectives lead to a stepwise and stratified work-up. The first step is to ensure ABO compatibility, then a clinical history and examination, urinalysis and further tissue-typing are carried out, together with counselling. If no contraindications are identified, a formal psychological assessment is arranged with an independent practitioner and further specific tests are organised, with the most invasive tests, including renal angiography, coming at the end.

Donor consent

Dr Robin Philpott (Mossley Hill Hospital, Liverpool) explored the issues around consent in LDTs. Ideally, the donor should approach the giving of a kidney as a pure act of charity, in a fully informed way, with a completely free choice. This ideal may be impossible to achieve as a full analysis of motivation is never possible, but it is the duty of doctors to ensure as far as possible that coercion and inducement, from whatever quarter, do not occur. Information for potential donors needs to cover the nature, the purpose and the risks of donation. Expanding on the last, Dr Philpott said that because the operation was unnecessary for the donor it was important to go into the risks in detail. For example, when things go well for the recipient, the donor experiences psychological benefit, but when things go badly for the recipient there is often an adverse psychological outcome for the donor, who might experience feelings of guilt, loss, blame etc. Such information should be given to a potential donor. It is also the proper business of the donor to know about the likely outcome for the recipient and what the alternatives are should transplantation not proceed. There should be no deception or persuasion.

Practicalities of living donor transplantation

Mr Geoff Koffman (Guy’s Hospital, London) described the surgical practicalities of LDTs. The elective nature of such transplants means that the surgery occurs in better conditions than in most cadaveric transplants, since LDTs occur during office hours with a full complement of staff and with support services readily available. The preferred method is to have two teams operating simultaneously on donor and recipient in adjacent theatres, since this reduces ischaemic time to an absolute minimum, but in some places the same team carries out both procedures sequentially. In Dr Koffman’s opinion, not enough LDTs are done to hone the specific skills of the teams involved, and he feels that more problems lie in the setting up of LDTs than in the doing of them.

Approaching potential donors

Kay Hamilton (Southmead Hospital, Bristol) spoke about her role as transplant co-ordinator. Her post involves both the procurement of cadaveric organs and the initial approach to, and subsequent counselling of, living donors. In her experience there is no one right way of going about things and the approach to potential living donors needs to be individually tailored. Meetings can take place in hospital or at home, with individuals, or with an extended family holding a group discussion. The initial approach may be made by a number of people, from a doctor to the potential recipient, but dedicated co-ordinators or counsellors have a specific role in carrying forward these approaches. To ensure the quality of consent it is her practice to discuss specifically the concept of gifting. An appropriately paced
stepwise work-up, coupled with ongoing counselling, mitigates against coercion by giving the potential donor several opportunities to bow out.

Potential problems

Dr Charles Newstead (St James' University Hospital, Leeds) had been asked by the conference's organiser to play devil's advocate to an audience with a clearly positive attitude to LDTs, and to highlight possible problems. He reminded the audience that some LDT kidneys will be lost early and that even successful ones may not last forever, so they must not be seen as a cure. But his greatest concern was quality of consent, particularly the difficulty in assessing its voluntary nature. He also referred to the potential blurring of the distinction between proper compensation and financial inducement.

Discussion

The conference ended with an open question-and-answer session, with Dr Douglas Briggs in the chair and Professor Andrew Bradley (Addenbrooke's Hospital, Cambridge) and Mr Chris Rudge (The Royal London Hospital) on the panel. The conclusion of the discussion was that living donor transplantation represents a positive and cost-effective response to the growing numbers on the waiting list for renal transplants, and deserves greater effort from health service professionals and more finance from the government.

Conclusion

The consensus of participants at this conference was broadly in favour of living donor transplants but it was felt that a more coherent national approach was needed. Indeed, the meeting itself had contributed in some way to this end. The invaluable contribution of transplant co-ordinators and counsellors was applauded, but there are not enough of them and hope was expressed that despite tight budgets new posts may be created. A joint working party of nephrologists and transplant surgeons is to be convened to address many of these issues.

Practical aspects of nutrition support

The British Association for Parenteral and Enteral Nutrition (BAPEN) was founded in 1992 in response to the recommendations of the King's Fund report, A positive approach to nutrition as treatment and was supported from the start by a consortium of the principal industrial companies providing nutrition support and pharmacy products. It has prepared a number of working party reports and runs training courses for nutrition support professionals. This first joint conference of BAPEN and the Royal College of Physicians took place in April 1998, and underlines the increasing recognition of the role of nutrition in patient care and the development of clinical nutrition as a medical specialty with an approved training programme.

Malnutrition related to disease

Dr C R Pennington (Ninewells Hospital, Dundee) presented data on the prevalence of disease-related malnutrition (DRM) in hospital, based on a study of 500 patients in five different specialties. Forty per cent of patients were underweight and 25% suffered moderate to severe DRM, defined as body mass index (BMI) of less than 20 kg/m². Fewer than 50% of these patients had a record of their nutritional status in their case notes and 75% of those with DRM continued to lose weight while in hospital. In some of these patients their malnutrition may have got worse because they missed some meals or could not eat what they had been given.

The difficulty of separating the effects of disease from those of undernutrition was repeatedly raised in discussion at this conference. The better progress of those patients whose DRM was recognised and treated supports the view that the effects of disease itself on DRM may often be reversed with nutritional support.

Dr J Edington (Abbott Laboratories, Maidenhead) had assessed the prevalence of DRM, in liaison with the MRC epidemiology centre in Southampton, in 474 patients with cancer, 2,959 with chronic diseases and 123 post-surgical patients in the community. DRM was more common in people in the lower social classes, in those under 65 years of age, and in women. Patients with chronic disease and DRM were more likely to suffer from apathy and those with cancer and DRM from chronic pain. Dr Edington also found that the rates of consultations, prescriptions, hospital admissions and mortality were all higher in underweight patients.

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