LIVE DONOR KIDNEY TRANSPLANTATION AND THE PLACE OF CHAPLAINCY IN THE DONOR ADVOCACY TEAM

Jen Lumsdaine and Anne Mulligan

Absract: These two pieces (one from a transplant co-ordinator and one from a chaplain) outline some of the ethical and pastoral issues raised in the increasing field of live donor organ transplantation. These include autonomy, 'first do no harm' and the support of families facing these decisions. The articles are based on the work of two members of staff in the Royal Infirmary of Edinburgh.

Keywords: live donor transplant, spiritual care, medical ethics, pastoral care

Living Donor Kidney Transplantation

Transplantation has been described as the most stirring event of the past century in the field of medical science. Many lives have been saved or transformed by organ and tissue transplantation, all made possible by donation from living or deceased donors, alongside the skill of surgeons and advances in drug therapy and clinical care. The concept of removing an organ or tissue from one person and transplanting it into another can in fact be traced as far back as the 13th century. Two physicians, Cosmas and Damian replaced the cancerous leg of a church sexton with the leg of a recently deceased man, and were subsequently honoured as patron saints of physicians and surgeons. Although many myths and legends were founded on the idea of transplantation, it was not until the 20th century that the concept became a reality.

The first successful living donor kidney transplant in the UK was performed in Edinburgh in 1960, between identical twins. The introduction of immunosuppressant drugs over the next two decades allowed both living and deceased donor transplantation for patients with end stage kidney disease. Regrettably deceased donor rates in most countries worldwide cannot meet the demand for transplantation. Currently in the UK more than 7000 people are awaiting an organ transplant. Over 6000 of these patients are on the kidney transplant list, and like other countries in the world the number of living donor transplants is increasing (almost 700 performed in the UK in 2006), there is still a shortage of organs for transplantation.

There is clear clinical evidence that, for the recipient, a living donor kidney transplant is the best option. The kidney is donated from a healthy person, who has been thoroughly investigated, the time the kidney is without a blood supply is very short, and the operation can be planned at a time that is optimum for the recipient. The difficulty arises with the complex ethical issues surrounding the removal of an organ from a well person and exposure of that individual to the risk of serious complications.

Each living kidney donor is carefully evaluated, encompassing both the physical and psychosocial health of the donor. This assessment usually takes between three and six months. The three main areas of physical assessment are summarized in Table 1.

Table 1: Three main areas of physical assessment for kidney transplant

Immunological compatibility	Blood group incompatibility, or the presence of antibodies that may react to the donor's tissue type, no longer excludes transplantation as alternatives such as antibody reduction and paired kidney exchange may be available
General health	To exclude co-morbidities that may increase the risk of major complications peri- and post-operatively. Risk reduction of disease transmission to the recipient (ie viral or malignancy)
Renal function	To ensure the donor has adequate renal reserve to live with a solitary kidney, and the recipient receives a well-functioning transplant.

Much time is spent with potential donor and recipient pairs with members of the transplant team, with written and visual information also provided, and each donor is informed of the short and long term risks of donation, including the risk of death (estimated at 1 in 3000 cases). All donors in the UK are also reviewed by an accredited Independent Assessor, as legally each transplant requires to be approved by the Human Tissue Authority.

The act of removing a well-functioning organ from a healthy individual for the benefit of another is a challenging concept and one that the transplant surgeon has to feel justified in doing on both medical and moral grounds. Inherently this is in direct conflict with the Hippocratic Oath of '*primum non nocere*' – first do no harm. However, living donor transplantation reaches beyond purely clinical factors. The surgeon has to assess the risk/benefit balance for the individual, examining the medical, social and psychological issues involved in each unique case. Is the removal of an organ from an otherwise fit person 'harm' or would the donor be 'harmed' by not being allowed to donate an organ to improve the life quality (or in some cases save the life) of a closely linked individual? A broader ethical view may be argued that an increase in living donation reduces the number of individuals waiting on the transplant list.

Although the final responsibility lies with the surgeon removing the organ, a team of health professionals assists with the evaluation process to reach the decision whether to proceed. Ultimately, only when consent by the potential donor and recipient is combined with the agreement of the team of health professionals that the balance of 'minimum risk to the donor and maximum benefit to the recipient' has been met, will living donor transplantation proceed.

Respect for an individual's autonomy is the basic ethical concept that gives each person the right to consent to, or refuse, treatment. However, individuals should be given the necessary information about the choices available and the potential consequences of each course of action. Whilst the potential donor may be given an appropriate, detailed description of the risks of donation, it is much less clear that all donors will listen. There may be a tendency for some people to decide at an early stage that they wish to donate and then to be impervious to any suggestion that they should make a more informed decision in the light of further counselling. The consent may be real but whether it is truly informed, is questionable.

It is also important to recognise that the clinical team involved also have rights as well as responsibilities. If a fully informed donor wishes to proceed with a course of action that involves risks of mortality or morbidity greater than the team find acceptable, they are under no obligation to proceed.

Jen Lumsdaine

Developments and Challenges in Organ Donation and Transplantation

The gift of an organ is a very precious gift. In the recent past we have become used to organ donation occurring from deceased donors. This is the result of

courageous and caring people being able to look beyond the tragedy that has happened in their lives in order to reach out to others in need and to permit their organs being used in this way. Many of us will have had the privilege as chaplains to sit with families in Intensive Care Units as they consider this and reach the decision to do what their loved one wanted, even if they are not sure if it is what they want themselves. Theologically speaking, organ donation teaches us so much about the power of light over darkness, goodness being stronger than evil and explicitly shows us how weakness and strength go hand in hand in God's grace.

As one parent was quoted as saying when his child was shot in a drive-by shooting and his organs were given for transplant. "We may be standing in the mud, but we can still gaze at the stars." (Reginald Green cited by Willis 1999). I am always moved by the ability of a family to look beyond the tragedy in which they find themselves, raising their sights to think about the needs of others. In the longer term I am sure it brings them comfort and contributes to their search for meaning in all that has occurred.

Those of us who work in hospitals with Transplant Units are fortunate to see the results of the gift of new life that the donation of an organ can bring. As well as involving a major operation, an organ transplant is also a very emotional experience for the recipients, many of whom feel quite overwhelmed when they reflect on the feelings of the donor family. Patients go through emotional highs and lows as they rejoice in the potential gift of new life which the surgery brings and begin to look to the future and, often having been near death themselves, reflect on what they imagine the donor family to be experiencing. There is also the additional factor that some recipients are aware that self-harm has contributed to their organ failure, alcoholism or drug overdose perhaps, and they feel the weight of responsibility to the donor, the donor family and their own family, of having being given a second chance.

In recent years we have seen a significant increase in the number of people receiving live donor transplants. This has raised a number of ethical issues and challenges for the medical profession. Do people have a right to donate an organ if that is what they choose to do? In today's society autonomy is recognised as perhaps the key ethical factor in medicine and medical law. The concept that individuals have control over their own bodies has dominated the control of medical practice more than any other in the last half-century. (Mason and McCall Smith 2006 p.7)

Autonomy, however is not an absolute principle. It does not imply that others are necessarily bound to co-operate. It can be overridden by the consideration of other moral claims. 'First do no harm' is a fundamental principle in medical ethics. Surgeons are being asked to perform operations on healthy people (the donor). This is not easy for them. The doctor is committed to acting in the person's best interests. Surgery which brings them no physical benefit does not fit in to that. But that which is medically in the person's best interest –or to put it another way – the person's best medical interest – may not in fact be the same as what is best for that person when regarded and respected as a human being. The person's whole life has to be taken into consideration, including what gives their life purpose and meaning. The relationship with the recipient is highly significant, as is the whole dynamic of the family. Any decision to be made by a potential donor is bound to be multifactorial and, as in many areas of life, our decisions with regard to our health are frequently made on an intuitive basis as well as a cognitive one. (Gorovitz 1982 p.38)

Kidney transplants from unrelated donors have increased so that we now see more spousal donations. The law has changed to permit altruistic donations although in reality it is still very rare for people to donate a kidney to a complete stranger except in the new developments in paired donations where two couples are matched in a crossover for donation because of different blood groups. The wife of patient A may donate a kidney to the husband of patient B and vice versa.

Chaplains who come into contact with families who are considering live donation are in a position to offer pastoral support as they face the issues involved. Some potential recipients are very moved by the offer of an organ from a loved one – though sometimes they find it very difficult to accept the offer, especially if it is coming from a younger generation. There are added complications when more than one person in the immediate family may be affected by a genetic illness e.g. polycystic kidney disease. A parent may want to donate a kidney to a child with renal

failure but will also have to face the possibility that a sibling has the same illness which could progress. Other issues arise in adult donation when a brother or sister may decide to donate to a sibling but the potential donor's spouse may not be so keen for this to happen. All sorts of family dynamics may surface and sensitive listening on the part of the chaplain may be appreciated, especially by the vulnerable patient who is coping with dialysis or deteriorating health (and possible death due to liver failure.)

In April 2006 the Scottish Liver Transplant Unit based at the Royal Infirmary of Edinburgh became the first NHS transplant unit in the UK to offer living donor liver transplants. This has come about because of the shortage of organs available and the resulting fact that one in five patients on our waiting list die before receiving an organ. Living donor liver transplantation was developed in Japan and is now common in the USA and parts of Asia and Europe. It has been made possible by advanced surgical techniques and the liver's ability to regenerate in both the recipient and the donor in 6-8 weeks. However the risk of death for the donor is very real and must be seriously considered. It is 1 in 200 compared to 1 in 3,000 in live donor kidney transplantation.

Following the death of a donor in New York in 2002, the US Dept. of Health and Human Services Advisory Committee on Organ Transplantation (ACOT) required all units undertaking such operations to establish a Donor Advocacy Team (DAT). The Scottish Unit has adopted this model too. This aims to ensure that there is a comprehensive and coordinated approach to the donor's welfare rather than just ensuring they are physically suitable to be a donor. The DAT's role is to assess the person's medical, psychosocial and social stability and suitability. At present the team consists of a consultant physician, a consultant psychiatrist, a transplant coordinator and myself as the chaplain. My role is to discuss with people their motivation for wanting to donate, ensuring there is no coercion from other family members, their relationship with the potential recipient, their ability to comprehend the risks involved and various other factors such as the support network they have in place. I may have already met the potential recipient and be in the unique position of offering support to both parties. All four members of the team must be in agreement that the person is a suitable donor before the transplant team proceed with the surgery. The other members of DAT work independently from the transplant team in that they have no contact with the recipient. Three out of four people should have a knowledge of and experience of transplant. Three out of four people should have no involvement in the work up of the recipient. All four members of the team must agree that the person is suitable to be a donor before the transplant team proceeds to the surgery.

This is the first such team to be established in Britain and it is a privilege to be invited to be part of it. There are on-going ethical issues to be wrestled with. Is it acceptable to expose someone to the risks of donation if, for example, the potential recipient is suffering from alcoholic liver disease? Should young people be permitted to donate to a parent or should it only be the other way round? What if there is a real risk of the initial disease recurring in the recipient's new liver? Can consent be ever 'fully informed'? These and many more issues are part and parcel of modern day medicine. However as live donor transplantation develops, and deceased donation continues, I find it both refreshing and challenging to meet with people who care and who are willing to make sacrifices for the benefit of others. It is a counterbalance to the predominance of individualism that influences much of modern society. While it is essential that strict control is exercised in the area of organ donation and transplantation, the generous donation of gifts of organs speaks to us of love and compassion and is surely to be encouraged and supported.

Anne Mulligan

References

ANDERSON-SHAW, SCHMIDT, ELKIN, CHAMBERLIN, BENEDETTI, TESTA 2005 Evolution of a Living Donor Liver Transplantation Advocacy Program. *The Journal of Clinical Ethics*

British Transplantation Society/Renal Association. United Kingdom Guidelines for Living Donor Kidney Transplantation. 2000.

British Transplantation Society/Renal Association. United Kingdom Guidelines for Living Donor Kidney Transplantation. 2005.

CABLE S, LUMSDAINE J and SEMPLE M 2003 Informed consent *Nurse Standard* 2003 Vol. 18 pp47-53.

GOROVITZ S 1982 *Doctor's Dilemma: Moral Conflict and Medical Care* New York Oxford University Press

KASIKE B L, BIA M J 1995 The evaluation and selection of living kidney donors. *American Journal of Kidney Disease* Vol. 26 pp387-98.

KUSS R, BOURGET P 1992 An illustrated history of organ transplantation. The great adventure of the century. France, Sandoz.

MASON J K, LAURIE G T 2006 *Mason & McCall Smith's Law and Medical Ethics* 7th Ed. Oxford, Oxford University Press

MILLER R B 2001 *Ethics and the kidney* New York, Oxford University Press

NEUBERGER J, PRICE D 2003 Role of living liver donation in the United Kingdom. *British Medical Journal* Vol. 327 pp676-79

RUSSELL S, JACOB R G 1993 Living-related organ donation: the donor's dilemma. *Patient Education Council* Vol. 21 pp89-99.

WADSTROM J 2005 *Living donor nephrectomy* UK, Taylor & Francis

WILLIS R W 1999 To what shall we liken the Hospital Chaplain? *Journal of Pastoral Care* Vol. 53.4 pp 391-94

WOODRUFF M F, ROBSON J S, ROSS J A, NOLAN B, and LAMBIE A T 1961 Transplantation of a kidney from an identical twin. *Lancet* 1 pp1245-9.

United States Dept. of Health and Human Services Advisory Committee on Organ Transplantation. 2002 Summary Meeting Notes www.organdonor.gov.acot11-02.html.

Jen Lumsdaine is the Living Donor Transplant Coordinator at the Royal Infirmary of Edinburgh.
Anne Mulligan is Chaplain to the Transplant Unit at the Royal Infirmary of Edinburgh.