Culture and psychology in organ transplantation

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The cultural and psychological dimensions of organ transplantation are often overlooked in the process of meeting its exacting technical requirements. This new branch of medicine has brought with it new ways of understanding death, human rights, commerce, gift giving, and ethics. It produces strong emotions in recipients, donors and transplanters alike. These factors need to be taken fully into consideration if organ transplantation is to evolve in ways that are felt to be beneficial for all concerned.

Research, experience and serendipity have all contributed to resolving many of the technical issues in organ transplantation. Societal concerns are now assuming greater prominence. Transplantation ethics, human rights issues, questions involving the human body and the protection of its integrity, the meaning and realities of organ donation, and the issue of brain death can only really be discussed sensibly when cultural contexts are evoked. In this presentation we begin by looking at a number of actual case histories which illustrate the interplay between transplantation, culture and psychology. We then explore briefly various issues of current interest in organ transplantation.

In our exploration we tacitly acknowledge the difficulties of cultural labelling, being aware of the enormous individual variation within cultures, and the uses and abuses of categorization (1). We do not see culture as an enemy that needs to be overcome to obtain patient compliance, nor do we see cultural understanding as an infallible guide to individual patient behaviour. We see it rather as one important factor among others that can help healthcare providers and planners deal appropriately with patients and with communities as a whole.

Case histories

During a recent visit to South Africa, we learnt of a young African girl who was successfully given a liver transplant. As often happens, her health was restored, she gained weight, and developed some of the body-image changing complications of immunosuppressive medication (such as round face and excess hair). Her friends thought she had become a witch, and they ostracized her. She stopped taking the drugs, rejected the liver and died.

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■ A young First Nations boy developed end-stage liver disease in Canada. His educated mother found out all she could about liver transplantation and decided not to subject her son to the procedure. She felt this would “violate his spirituality.” The authorities, wanting to protect the child, took her to court. She won, and the authorities chose not to appeal. Soon after, the boy died peacefully (2).

■ An American woman visiting Guatemala stopped on the street to talk to some children, unaware of the strong belief locally that missing children were kidnapped and their organs used by Americans for transplantation. She was immediately surrounded by a crowd, which proceeded to beat her up badly. When we last heard of her, she was unconscious in an intensive care unit.

■ A member of the white supremacist Ku Klux Klan was offered for transplantation the kidney of a deceased African American. He turned it down. After months more on dialysis, and on reflection, he accepted the next kidney, also from an African American. When his health was restored, he felt so transformed that he went on to become an activist for the National Association for the Advancement of Coloured Peoples.

■ Members of the Jehovah’s Witnesses church do not accept blood transfusions. Explaining to them that organs can be washed completely of traces of blood has allowed them to accept kidney transplants. A recent report documents eight successful kidney transplants for Jehovah’s Witnesses, both from cadavers and from living donors (also Jehovah’s Witnesses) without the use of blood before, during or after the operations.

■ In Singapore, like everywhere else in the world, there is a shortage of organs. The Human Organ Transplant Act authorizes the removal of organs from a brain-dead person unless that person has expressed an objection to this procedure (presumed consent). Muslims objected as a group, and were specifically excluded in the law. As a result, they very rarely receive an organ transplant.

■ Belgium enacted a “presumed consent” law about a decade ago. Jews, mainly orthodox, working in the diamond trade in Antwerp, were among those who registered their objections in large numbers, and have therefore not become donors.

■ Withstanding pressure from Orthodox Jewish Rabbis in Israel to transplant Jewish organs only to Jews, transplant surgeon Dan Shmueli was quoted in Newsweek as saying “I only have patients, not Jewish patients”.

■ Maoris in New Zealand and Aborigines in Australia have high rates of end-stage renal failure and are over-represented on waiting lists. Yet their cultures do not allow them to donate organs after death. Therefore, like many Asians in the United Kingdom, they receive organs but do not donate. Many others resent this.

■ African Americans in the USA are over-represented on waiting lists. They have been reluctant to donate in some states, do poorly after transplantation, and are penalized when histocompatibility is used as an important criterion for organ allocation, because of the differences in the genetic make-up between them and the majority. Clive Callender and his colleagues in Washington (3) have looked at the reasons for the poor donation rates among African
Americans and found distinctly cultural reasons such as religious myths and misperceptions, distrust of the medical community, fear of premature declaration of death after signing a donor card, and black donor preference for assurance of black receivership. Dealing with these concerns through education and information activities has had a positive impact upon donation rates.

These brief case histories illustrate several aspects of the impact of culture and psychology on organ transplantation. We explore some of them below.

The question of death

Transplantation started in 1954 with living donors but by the 1970s the main organ source was cadaveric donors. The whole field was energized by the adoption of brain-death criteria for diagnosing death in patients on ventilators in intensive care units. Pallis (4) has written extensively on the subject of brain death. As a neurologist, he has studied death in many cultures, and his writings correctly acknowledge the part played by culture in defining death. However, he concludes categorically that death is and has always been of only one kind: brain death. From the purely physiological and technical perspective, we share this view, but it does not negate the need to be sensitive to various cultural issues when discussing the subject.

Indeed, it means that sensitivity is indispensable if educational programmes are to succeed, and if the right decision is to be made about whether to introduce the concept in some cultures. The adoption of brain-death criteria has occurred without much societal debate and to a large extent has ignored the reality that death is a cultural construct. Margaret Lock (5) and Emiko Ohnuko-Tierney (6) have both written about the unwillingness of the Japanese to accept brain death. Reasons cited include beliefs about what happens to the person after death, cultural resistance to mutilating the body, and the idea of impurity associated with the dead body. There are, of course, many other considerations, including the history of transplantation in Japan, with a notorious case in which a heart transplant was performed before the population was really ready for this. In a recent article Margaret Lock comments that perhaps the most important question to ask is not why the Japanese have refused to accept the concept of brain death but rather: why did North America and most of Europe “accept the remaking of death with so little public fuss” (5)?

In Hinduism, Christianity and Islam the debate about organ transplantation and brain death continues, but for all three the majority opinion now is that brain death is acceptable. Interestingly, some German theologians have recently reopened this subject and a vigorous debate is now going on, slowing down the passage of a transplant law in Germany. In Hinduism, the theory of karma and the philosophy of helping others both favour transplantation, while other traditions such as cremating the whole body and belief in the untouchability of the body could be used as arguments against cadaveric organ donation. In Buddhism, life itself is an
illusion and death is the temporary end of a temporary phenomenon. Not much significance is attached to the body after death, although it is considered a good thing to respect it. Thus there is no contradiction to either living or cadaveric donation and transplantation.

So far, however, attempts to win recognition for brain death and promote cadaver donation in developing countries have not been widely successful. There are many reasons for this, but one of the most important is the difficulty of explaining the concept to the lay person. Without a deep understanding of the culture concerned, and of the meaning of death in that culture, the effort seems doomed to fail.

Human rights issues

Organ transplantation raises complex and little-studied human rights issues such as bodily integrity and freedom from physical harm. At the request of the World Health Assembly in 1987, WHO drafted guiding principles for human organ transplants, and a number of other international initiatives have been taken to overcome some of the inherent dangers, particularly those related to the trade for profit in human organs. Efforts have been aimed at building up a just distribution system and an equitable rate of donation.

Schepers-Hughes asserts that if cadaveric organs were obtained in an environment of political repression where “disappearances”, torture and the like were practised, this would represent an abomination, another form of violence. In such circumstances “the most vulnerable people will fight back with the only resources they have, gossip and rumours” (7). The important point she makes is that the stories told are believed by the local population, whether or not they can be verified, and as such they influence behaviour. Thus violence, the disappearance of street children, baby adoption rackets, the use of organs obtained from executed criminals and other such issues and fears have to be fully recognized and dealt with if organ transplant policies are to obtain the credibility they need in order to be effective.

Cultures within the enterprise of transplantation

The approach of Dr Christiaan Barnard, the surgeon who performed the first heart transplant in 1967, contrasted strongly with that of the team led by Dr Norman Shumway at Stanford University. The latter had been working in the laboratory methodically to learn as much as possible before embarking on clinical transplantation, and was overtaken by the brash young South African. As it turned out, the knowledge and experience base was inadequate at the time, and after a number of teams had jumped onto the bandwagon with disastrous results, an embargo was proclaimed on heart transplants.

This lasted until Shumway’s team, after much more research, gradually reintroduced the practice of heart transplantation based upon a more solid foundation. Today, this is seen as a success, but in the eyes of critics of transplantation there is
now, particularly in some transplant centres in the United States, a culture of institutionalized optimism which borders on the unacceptable. Renée Fox recently criticised a protocol used to obtain organs from persons who had previously been not to be aggressively treated if they developed terminal illness as “an ignoble form of cannibalism” (8). Even within the same country, however, there is a sharp contrast between this culture of excessive zeal and the more predominant one of careful research. Despite various misgivings, transplantation today is a well-established mode of therapy, practised, on the whole, by caring physicians who adhere to accepted ethical principles and the guidelines of the Transplantation Society.

Questions of commerce

In the border area between donation and sale, and between acceptable and unacceptable forms of payment, is a category of issues that we have called “the grey basket”. Approaches include separating the act of donation from the act of exchanging money, and taking fully into account the different economic and cultural circum-

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stances in which such transactions take place. The Islamic Republic of Iran has a large and transparent programme involving what Iranians consider to be a culturally acceptable form of monetary compensation for kidneys obtained from living unrelated donors. Dr Reddy and his colleagues in Madras have eloquently defended and rationalized their form of paid donation (now illegal under the new law on transplantation) wherein middle-men were eliminated, donors were selected after psychological evaluation, fixed payments were made transparent, advice was given on investing the money, and donors were insured for sickness benefits for three years after donation. All these approaches have been criticised but, obviously, they also have supporters. The subject is complex and can only be discussed sensibly when cultural, political and economic realities are taken into account. Our own view is that beliefs about proprietorship over human body parts and the capacity to provide consent for organ donation are culturally constructed (9).

In the United States, a “futures market” in cadaveric organs has been proposed and, to the surprise of outsiders, was endorsed two years ago by the American Medical Associations. It is difficult to imagine this happening in any other country. The United Network on Organ Sharing (UNOS) and most of the transplant community have rejected the idea. However, the idea of giving the family of the recently deceased a monetary incentive for organ donation has been seriously considered, and in Philadelphia (USA) it is being put into practice. India has now adopted the Human Organ Transplant Act, which is aimed at abolishing commerce in organs for transplantation while at the same time recognizing brain death and facilitating cadaveric organ donation. It is too early to judge the effects of this law.

Official religious views on the question of payment for organs tend to hinge on casuistic, technical and legal arguments. Payments, under very specific circum-
stances, are permissible in Islam, and the technical appropriateness of payment has been repeatedly affirmed by various Jewish scholars. Nevertheless, the majority of religious leaders and those in the profession do not think it wise to purchase organs, arguing that it will always be the rich who receive and the poor who give, that selling organs demeans human beings, and that there will be abuses because regulation will be difficult to enforce.

The metaphor of the gift

The “gift of life” was a metaphor adopted quite early in organ transplantation. Fox and Swazey have noted that transplantation has lost this rather spiritual connotation and become “routinized” for the profession – though it has not done so for the public. They talk of the “tyranny of the gift” in transplantation, where there is no way to repay this priceless gift, for the cadaveric donor is dead and the recipient is usually forbidden even to meet the donor’s family to express gratitude face to face. In living donor transplants, the obligations involved can in theory create an unhealthy atmosphere between donor and recipient, though in practice this is not a common problem, and often the opposite happens.

The classic work on the subject of gifts is Marcell Mauss’s *The gift: forms and functions of exchange in archaic society* (10). The title of the book contains the essence of its argument: a gift is an “exchange” if it is to have any societal value. It is then understandable that some commentators question the appropriateness of the gift paradigm in cadaveric donation, a process in which the relatives decide and the “donor” is dead and there is no opportunity for reciprocation.

The transformation of ethics

The paternalism encouraged by Hippocratic ethics is ingrained in many physicians, having stood the test of time in patient–doctor relationships, and in many countries it continues to provide the main basis for health-related discussions. However, with increased patient awareness, individualism, autonomy, and particularly the economically and politically sensitive issue of distributing scarce resources (such as dialysis facilities and organs for transplantation), views have changed considerably. The traditional “professional ethics” of medicine is being supplemented by what in North America is called “bioethics”. In this cultural milieu, the physician is only one in a team of decision-makers, and management decisions can often be suggested by the patient or other members of the team. These include the resident consultant on ethics, who is often a philosopher or a priest rather than a physician.

The current ethical situation is not entirely satisfactory, and several thinkers have been calling for a re-evaluation. Certain broad trends can be discerned in the direction bioethics is taking. Most would agree that, at present, the predominant model is based on Western notions of the individual imbued with personal autonomy living in a liberal democracy. The Western, particularly American, sense of the body and personhood is expressed in rational, legalistic, rights-oriented, individual terms. These include a number of dichotomies such as body/mind, thought/feeling, conscious/unconscious, self/other, reality/non-reality. In many other cultures, by contrast, the sense of personhood is expressed rather as relationships, solidarity, interdependence, reciprocity and mutual
obligations, or what has been described as the “fractal person” (11).

Many are now beginning to question the supremacy of the “big four” values of autonomy, beneficence, non-maleficence and distributive justice. Various authors are looking beyond these to models of ethics based on concepts such as casuistry, virtue ethics, relational ethics, hermeneutics and narrative ethics. These have been reviewed by Marshall and Koenig (1). As Marshall has said elsewhere (12), there is a need to get away from high theoretical abstraction to “the complicated human settings and interactions within which moral dilemmas are culturally constructed, negotiated and lived”. Hence the need for an effort to “humanize bioethics” (1).

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Psychological aspects of organ transplantation

**Recipients**

Usually, a person finds it devastating to learn that his or her life depends from now on on artificial support. In the case of dialysis, family, friends, work and leisure are affected, income is reduced, and sexual impotence frequently sets in. While many patients adjust well, there is a large group of psychological hazards, perhaps the most common being depression. Coping strategies include denial and suppression early on, followed later by a more active interest in spirituality. A distinct way of life develops among dialysis patients, revolving around the dialysis machine and the health care staff. It is a culture of dependence and uncertainty on the one hand, and hope on the other (for the day when the patient will receive a transplant).

Without adequate psychological preparation, even a technically perfect transplant can fail, particularly if the recipient does not comply with follow-up routines, frequent check-ups, and drug and diet advice. Immunosuppressive agents like cyclosporin A and steroids can cause highly visible bodily changes which alter the patient’s self-image. These include obesity, rounded facies (Cushingoid changes), an overgrowth of facial hair and gingival hypertrophy. These changes, particularly in teenage girls, can cause severe psychological problems requiring help from professionals other than transplant physicians. Factors such as substance abuse, personality disorder, and problems with living arrangements and education have been found to correlate with poor compliance and increased rejection episodes in transplant patients (13). There is therefore a need for pre-transplant evaluation of such factors, and education on them, to avoid negative outcomes. Nevertheless, a number of studies have shown a much higher level of psychological well-being after transplantation than before. The patients’ quality of life is improved both physically and psychologically, and there is a sense of restoration and regaining control over one’s life (14).

Following transplantation, relief and hope in the early phase are offset by fear of rejection (14). Rejection of the graft, if not lethal (more common with heart and liver transplants than kidney transplants), can
be a devastating experience for the recipient, especially where the period on the waiting list for cadaveric organs has been long.

**Donors**

Relatives of a person who has just died in the intensive care unit are likely to be in an extremely vulnerable state. If they need to be approached for permission for donation of the organs of the deceased, this requires care, experience, and sensitivity. The European Donor Hospital Education Programme educates transplant coordinators, nurses, physicians and others called upon to deal with relatives in these very trying and sad circumstances (15). The positive aspect of this situation is that it gives relatives a chance to salvage something good and hopeful out of a tragic situation beyond their control. Psychological points to be aware of include fear of delays in organizing the funeral, fear of mutilating the body, and the desire to be close to the deceased.

For living renal donors, the act of donation has been repeatedly described as perhaps the most altruistic and meaningful act that a human being can perform to help another. The psychological reward for the donor has been documented as including emotional, spiritual and psychological benefits; there is increased self-esteem (14), and the satisfaction of seeing a loved one restored to good health. The Munich Protocol (16), which includes intensive psychological interviews of potential living renal donors and recipients, discusses not only the benefits but also worst-case scenarios such as death, divorce and rejection. The results have been so impressive that recently a well-known German transplant surgeon, Professor Jochem Hoyer, decided to donate one of his kidneys to an unknown recipient.

**Transplanters**

Transplanters live with uncertainty all the time; they tend to be risk-takers who are perpetually under stress, particularly as they are placed between end-stage organ failure and death on the one hand and the possibility of radically changing the situation on the other. Psychologically they tend to be optimistic, daring and aggressive.

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Culture plays an important role in the perception of illness, response to treatment, and the organization of medical care. In transplantation, cultural considerations arise in relation to the acceptance of this mode of therapy, the issues associated with consent to donation, the organization of the transplant programme, the type of transplant performed, and the outcome of transplantation. Many cultural factors also interact with well-known psychological problems associated with the state of chronic ill-health. These include dependence on machines, medication and other people; the effect of illness on work, income, family and leisure; and the side-effects of immunosuppressive medication. The symbolism and beliefs attached to various organs, especially the heart, can be a strong influence in hindering development of transplantation. Certain societies have various reasons, including cultural
ones, for finding it difficult to introduce
and accept brain death as tantamount to
death. The cultural aspects of organ trans-
plantation provide rich material for
intercultural dialogue, which could signi-
cantly deepen mutual understanding.

References
1. Marshall P, Koenig B. Anthropology and bioethics:
perspectives on culture, medicine and morality. In:
Sargent C, Johnson T eds. Medical anthropology:
contemporary theory and method, 2nd ed. Praeger

2. Paulette I. A choice for K’aiia. Human medicine,

3. Callender CO et al. Organ donation and blacks: a
critical frontier. New England journal of medicine,

In: Morris PJ, ed., Kidney transplantation –
principles and practice, 4th ed. Philadelphia,

5. Lock M. Ideologies and brain death in Japan. In:
Younger SJ, Fox RC, O’Connell LJ, eds. Organ
transplantation: meaning and realities. Madison WI,

6. Ohnuki-Tierney E. Brain death and organ
transplantation: cultural bases of medical
242.

7. Scheper-Hughes N. Small wars and invisible
genocides. Social science and medicine, 1996,

8. Fox RC. An ignoble form of cannibalism: reflections
on the University of Pittsburgh Medical Center
protocol for procuring organs from non-heart-
beating cadavers. Kennedy Institute of Ethics

human organs: the autonomy paradox. Theoretical
medicine, 1996, 17: 1–18.

10. Mauss M. The gift: forms and functions of
exchange in archaic societies. Glencoe IL, Free

11. Taylor CC. Condoms and cosmology: the “fractal”
person and sexual risk in Rwanda. Social science
and medicine, 1990, 31(9): 1023–1028.

12. Marshall P. Anthropology and bioethics. Medical

13. Shapiro PA et al. Psychosocial evaluation and
prediction of compliance problems and morbidity
after heart transplantation. Transplantation, 1995,
60: 1462–1466.

14. Franklin PM. Psychological aspects of kidney
transplantation and organ donation. In: Morris PJ,
ed. Kidney transplantation, principles and practice,

15. Wight C. Organ donation – a way forward? In:
Johnson RWG, ed. Transplantation 1996:
Maximising patient benefit in transplantation.
(International Congress and Symposium Series No.
217).

evidence-based justification for ethical option.