Chapter 9

Personal and social effects of xenotransplantation

9.1 A health care system is part of a wider social order. Developments in health care cannot, therefore, be separated from their social context and the broader effects they may have. It is difficult to predict how social attitudes and institutions will respond to xenotransplantation, should it become introduced as a clinical treatment. It is important to consider what these responses might be, however, even if there is, inevitably, an element of speculation involved. In this chapter, therefore, the broader social implications of xenotransplantation are considered.

Attitudes towards xenotransplantation

9.2 One view of xenotransplantation is that it represents yet another attempt by human beings to deny their own mortality. Susan Roberts wrote in her submission: "*For whilst the improvement in medical techniques is an admirable challenge to face, we do appear to be driven by an overriding desire to fight death at all costs. Perhaps if we could come to terms with the forces of nature at work within our own lives, it would enable us to reach a position of equanimity with the rest of the planet.*" This view reflects a more general ambivalence about 'high-tech' medicine that is sometimes thought not only to yield little benefit in terms of increased quality of life but also to undermine human dignity in death.[1] Survey respondents, for example, often express a preference for treatments that reduce pain or disability over those that add a little to the length of life. These reservations extend to human organ transplantation. There is also concern about the morality of practices associated with obtaining human organs for transplantation (paragraphs 2.6 - 2.10). Underlying these attitudes is a sense of the inherent limitations of modern medicine, and a recognition that death can be staved off a little but never defeated. In this context, xenotransplantation can be regarded as part of the quest to prolong life, in pursuit of which goal, human beings are prepared to abuse their relationship with other animals.

9.3 Transplantation does not have to be regarded, however, as a form of heroic intervention that strives to extend life at any cost, with little regard to the best interests of the patient. As discussed in Chapter 1, transplantation is increasingly a routine, and not especially expensive, form of treatment that offers significant

[1] Calman M and Williams S (1992) Images of scientific medicine. **Sociology of Health and Illness,** 14:233-54.

improvements in length and quality of life and, were it not for the organ shortage, could do so for a large number of people. In this context, xenotransplantation if clinically effective, might offer a way of alleviating the organ shortage that would reduce the need for controversial measures to increase the supply of human organs. The use of animals, while undesirable, might be seen as raising ethical difficulties less severe than those that arise in solving the organ shortage by other means (Chapter 2). In a study of young people's attitudes to xenografts in the UK, while concerns were expressed about this use of animals, 55 per cent considered that research to develop pig organs for transplantation should continue (45 per cent opposed it).[2] Many of the those who wrote to the Working Party expressed profound sympathy for the plight of people in need of treatment and the hope that xenotransplantation might offer a solution. These views were combined with a recognition of the need for safeguards to ensure the protection of both human beings and animals (paragraph 1.32).

9.4 The concerns expressed about medical developments in general, and about transplantation and xenotransplantation in particular, highlight the importance of transparency and openness in the activities of researchers and policy-makers involved in xenotransplantation, and of full debate across society about its acceptability. The National Spiritual Assembly of the Bahá'ís of the UK stressed the importance of ongoing consultation and the "*seeking of the views of the wider community.*" If these measures are fulfilled, attitudes to xenotransplantation will reflect informed and considered opinion. This should also reduce any danger that xenograft recipients would be stigmatised in any way.

Effects of xenotransplantation for individual recipients

9.5 An important question is how xenotransplantation might affect individual recipients. A person's self-image is clearly related to their perception of the body. When assessing the impact of xenotransplantation, it will be necessary to consider how a person's perception of their body, and of their identity or self-image, is affected. A person's sense of identity also depends on a history of involvement with other persons, as well as with other elements, both animate and inanimate, of the environment. Thus, the impact of xenotransplantation will depend to an extent on the responses of health care workers, carers, family members and others close to xenograft recipients. Any assessment of xenotransplantation should take into account its potential impact on these relationships.

[2] This was part of a project funded under the BIOTECH programmes entitled **Cultural and Social Objections to Biotechnology: analysis of the arguments with special reference to the views of young people**. Dr Mairi Levitt described the project in her submission to the Working Party: 238 students, aged 11-18 years, from three different schools were given background material about xeno- transplantation and then answered a questionnaire.

9.6 In trying to assess how people might adapt to xenotransplantation, it is helpful to draw on research that has examined the personal impact of human organ transplantation.[3] This research indicates that how well, or badly, someone adapts to transplantation can have a significant impact on physical recovery and on health. In particular, there may be a direct effect on the level of compliance with the demanding regime of immuno-suppressive drugs and other follow-up procedures needed by transplant recipients.

9.7 The stresses of human organ transplantation fall into two classes: those experienced before transplantation, and those occurring afterwards.[4] The stresses before transplantation include dealing with the effects of a severe illness, and coping with the long wait for a transplant and the uncertainty of a suitable organ or tissue becoming available whilst being close to death.[5] If xenotransplantation succeeds in alleviating the shortage of organs for transplantation, making transplantation available more quickly and to more people, these stresses might be significantly reduced.

9.8 Stresses occurring as a consequence of transplantation include the general stresses of hospitalisation and surgery. More specific stresses include coping with the fear of rejection of the transplant or with infection; with the intrusive nature of immunosuppression and follow-up treatment; and with a change in image of the body.[6] Different levels of significance are attached to different transplants: tissue transplantation, for example is seen as much less significant than organ transplantation. Heart transplantation is seen as most significant, since so much symbolic importance is attached to that organ: "*It is the seat of emotions (especially love) courage, enthusiasm and innermost thoughts.*" [7] Transplant recipients report being affected by thoughts of organ donors and their families. For some, it is disturbing that they have inside them an organ from someone who has died.[8]

9.9 There is evidence that transplantation is particularly stressful for children and adolescents.[9] Young children may not understand why they are ill, and may perceive it as punishment. Self-image and the peer group are particularly important for adolescents, and this may lead to problems with adjusting to receiving a transplant, coping with scars and the physical side-effects of immunosuppressive drugs. Adolescents' increased desire for independence may lead to resentment of the

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[3] Craven J and Rodin G M (1992) **Psychiatric Aspects of Organ Transplantation**. New York: Oxford Medical Publications.

[4] Craven and Rodin (1992) **Psychiatric Aspects of Organ Transplantation,** pp 90-7.

[5] British Heart Foundation (1995) **Cardiac Transplantation**.

[6] Craven and Rodin (1992) **Psychiatric Aspects of Organ Transplantation**, pp 95-7.

[7] Submission to the Working Party from the Working Group on Genetic Engineering in Non-human Life Forms of the Society, Religion & Technology Project of the Church of Scotland.

[8] Craven and Rodin (1992) **Psychiatric Aspects of Organ Transplantation**, pp 169-71.

[9] Craven and Rodin (1992) **Psychiatric Aspects of Organ Transplantation**, pp 33-49.

restrictions associated with immunosuppressive drug regimes and problems with compliance.

9.10 How might the stresses of xenotransplantation compare with those of human organ transplantation? For early recipients, at least, fear of transplant rejection is likely to be very real. Follow-up will also be very demanding, since it will involve procedures to monitor possible transmission of animal diseases (paragraphs 6.33 - 6.37). Compliance, or otherwise, with such monitoring will have implications not just for the health of the individual recipients, but possibly for the wider community.

9.11 It is difficult to predict how people's views of their bodies and of their identities, might be affected by xenotransplantation. On the one hand, the use of animal organs might eliminate any disturbing implications associated with receiving a human organ. On the other hand, receiving an animal transplant might cause different stresses. The response is likely to reflect notions of what it is to be a person, to be human and to be an animal. These notions are not uniform for this or any other society, but vary according to social and cultural background. A small UK survey has shown that 40 per cent of potential recipients would have no objection to receiving a pig kidney. A US survey of transplant recipients found that they were more likely to say they would accept a xenograft if they needed another transplant and no human organ was available.[10] An Australian survey of acute care nurses found that two-thirds said they would not accept transplantation of an organ from a pig.[11]

9.12 One cause of unease is the breaching of normally inviolate boundaries.[12, 13] This is seen in human organ transplantation. The recipient of a transplanted organ may feel that the boundary between self and non-self has been breached. As described above, receiving an organ from a dead person may also disturb the recipient. With xenotransplantation, an additional boundary, that between human and animal, may become blurred. Whether, or in what ways, this is perceived as a problem will depend on how the human being-animal boundary is defined and the significance that is attached to it. If the essence of humanity is seen as a capacity to transcend the level of organic existence, then a person's sense of identity should not, in theory, be threatened by a transfer of organs across species boundaries. The idea of xenotransplantation may become troublesome if there is not thought to be a strict division between humanity and bodily existence. In this case, to receive an organ

[10] The UK study was carried out at Guy's and St Thomas's Medical and Dental School, London and presented at the British Renal Symposium, Harrogate in 1994. The US study was carried out by the National Kidney Foundation (NKF Survey reveals positive feelings on animal-to-human transplants (1995) **Dialysis and Transplantation,** December 1995, p 677). These surveys were described in the submission from the UK National Kidney Federation.

[11] Mohacsi P *et al.* (1995) Letter to **Nature**, 378:434.

[12] This section draws on the submissions from Marilyn Strathern and Tania Woods.

[13] Fox R (1995) Presentation at an Institute of Medicine conference on Xenograft transplantation: science, ethics and public policy, Washington DC.

from another animal might be seen as a mixing of one's human essence with that of the animal, and therefore as a dilution of one's humanity. Xenotransplantation will be troublesome for a different reason if it is felt that some or all of those characteristics by which human beings are recognised as persons are also shared by animals (paragraph 4.13). To receive organs or tissue obtained by killing a healthy animal might then be seen as objectionable.

9.13 It is sometimes argued that if receiving an animal transplant was particularly disturbing to pig heart valve recipients this would have emerged as a problem by now. As mentioned above, however, the significance of a transplant varies, depending on the particular organ or tissue (paragraph 9.8). Pig heart valves are small pieces of tissue that have been treated to make them non-viable. The possibility that someone might react much more strongly to transplantation of a vital organ from an animal cannot be dismissed.

9.14 The submissions received by the Working Party contained a range of reactions to the idea of xenotransplantation. Sheila Silcock asked "*Might there be such a thing as emotional rejection? Suppose a patient suddenly had a revulsion about having received an animal organ. Counselling prior to organ transplant is essential and would presumably be even more vital before a xenotransplant.*" Audrey McLaughlan reported that "*patients in the Renal Unit mentioned that they had qualms about having animal organs within their bodies.*" Students from Dalriada School in Northern Ireland had a variety of opinions. Some said: "*I would be prepared to accept an organ from a pig.*" and "*using a pig organ in your body is better than dying.*" Others said: "*we have been made superior to animals and it would be degrading to be made of part pig, part human*" and "*the concept of an organ being part of me seems quite distasteful*". How xenotransplantation might be regarded by people who view the pig as ritually unclean was discussed in Chapter 4 (paragraph 4.24).

9.15 Predicting how people might feel if xenotransplantation were performed on them or on someone close to them, is very difficult. Virtually nothing is known about the effects of xenotransplantation upon perceptions of identity, whether for xenograft recipients or amongst those who care for them or interact with them in other ways. This highlights the need for more research into these issues. **The Working Party recommends that counselling of xenograft recipients should include discussion of the possible personal impact of xenotransplantation. The Working Party further recommends that research should be initiated to study the personal impact of xenotransplantation on potential and early recipients.**

The implications of xenotransplantation for attitudes to human organ donation

9.16 An important concern raised by xenotransplantation is the possible effect upon willingness to donate human organs. Relatives and friends will often find solace in the knowledge that the death of a loved one has not been entirely futile but has given the gift of life to another. The organisation called BODY has been established to bring together relatives of donors. They provide examples of families who say that it has been a great comfort to them to know that the organs of a loved one have given life to someone else.[14] In one case, parents who agreed to the transplantation of their dead son's kidney value an anonymous letter from the recipient's mother as among their most treasured possessions. The gratitude of recipients is also striking. One liver transplant patient has said that not a day goes by without her thinking of the person whose liver she received.[15] Thus, the present system of human donation creates a delicate web of relationships among members of society that reflects a commitment to social solidarity and mutual concern.

9.17 The willingness of human beings to donate their organs, however, is hard to sustain (paragraphs 2.7 - 2.8). Quite a small amount of adverse publicity will have large effects on rates of organ donation. Conversely, it is an uphill struggle to increase the number of people registered as organ donors, even despite initiatives such as the NHS Organ Donor Register.[16] It appears that the ethical concerns and anxieties people have about organ donation are only partly overcome by the sense that organ donation is the ultimate gift in that it allows someone else to live.

9.18 In this context, there is a danger that xenotransplantation could jeopardise the willingness with which human organs are donated. This may be for two reasons. Firstly, early publicity about successful xenografts could lead potential donors or relatives to think that it was no longer worthwhile to register for organ donation; people might assume that the use of animal organs had eliminated the need for human organs. Secondly, unease at xenotransplantation might increase the general concerns about organ transplantation and lead to a fall in the donation of human organs.

9.19 It is highly unlikely, however, that xenotransplantation will eliminate the need for human organs. In the near future, at least, xenografts are unlikely to be as successful as human organ transplants. The most likely outcome is that xenotransplantation will ultimately become part of a range of strategies that could be used in the

[14] The British Organ Donor Society (BODY) (1991) **The Gift of Life: An introduction to organ and tissue transplantation**.

[15] Brooks G (1995) Comments at an Institute of Medicine conference on Xenograft transplantation: science, ethics and public policy, Washington DC.

[16] For information about the NHS Organ Donor Register, freephone 0800 555777.

treatment of organ failure, alongside human organ transplantation, and the use of artificial or bioengineered substitutes. It is very important, therefore, to indicate to potential and actual donors that their gift is no less precious because a development involving animals has now become part of the repertoire of treatment. A particular concern is that xenografts are unlikely to be uniformly successful across different organs and tissue. For example, the use of animal organs for liver transplants presents more difficulties than the use of animal organs for heart transplants because of the liver's complicated biochemistry (paragraph 3.6). Thus, it will remain essential to maintain levels of human organ donation.

9.20 There is a great responsibility, therefore, on xenotransplant teams, on the media and on those responsible for influencing public opinion to ensure that the reporting of developments in xenografts is as accurate, balanced and unsensational as possible. The temptation must be resisted to report early animal or clinical trials as scientific breakthroughs that presage a speedy solution to the problems created by the shortage of human organs. It should be clear from this report that, for the foreseeable future, xenotransplantation will not solve the shortage of organs for transplantation and that there will still be a pressing need for the donation of human organs.