
BIOETHICS OUTLOOK

John Plunkett Centre for Ethics in Health Care

Volume 7 Number 2

June 1996

“Opting-Out” vs “Hot Pursuit”— Organ Donation and the Family

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Organ donation rates vary markedly throughout the world. Australia's rate is low, and has fallen over the last decade, so that the annual rate is now less than 10 per million population. Most Australian transplant projects are severely restricted by the critical shortage of available donor organs. This is despite the fact that the success rate for transplant surgery is high. For example, the one year survival rate for a kidney graft is 85%, for a heart transplant 92% and for a liver transplant more than 80%.¹ Meanwhile waiting time for transplantation of a heart or a liver is three to six months, and one in five potential recipients will die before a suitable organ becomes available.

Given these facts, it is not surprising that those involved in transplantation medicine have sought ways to increase the rate of organ donation among the Australian population. Public education campaigns (which are limited because of the minimal public funding available for advertising) have failed to increase donor rates in a sustained way. Since the number of potential donors each year is greater than the number of actual donors, some have sought to

change our approach to organ procurement in order to increase the donation rate.

In this paper I will consider two possible changes to the organ procurement system in Australia which might increase donation rates. The first involves using an “opting-out” system, where all individuals who die are considered to have given a “presumed consent” to donation unless their contrary wish has been documented prior to death. The second, currently being considered by the South Australian Health Department, is modelled on the centralised organ procurement system introduced in Spain in 1989, which produced a dramatic increase in donation rates. Both of these alternatives, their proponents claim, could improve the “efficiency” of organ procurement procedures, and so decrease the “waste” of potential organs.

A Worthy Goal

The desire for an efficient organ procurement programme is a worthy goal. The needs of potential recipients - whose quality and length of life depends on receiving a transplanted organ - make an ethical demand on doctors to strive for efficiency in this sense. The duty to manage scarce medical resources responsibly makes a similar demand. Efficiency must not be purchased at a cost which is too great, however. Improvements in efficiency must not be at the expense of human dignity or donor altruism or autonomy.

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Both the Spanish system and the "opting-out" system raise the contentious question of consent to organ donation, and set the scene for a discussion of the social and ethical significance of the family of potential organ donors as a way of reflecting on the problems and benefits of attempts to improve the organ donation rate in Australia. In the case of an "opting-out" policy, the putative benefits may be outweighed by the ethical cost. However, I will suggest that the Spanish model, or some modified form of it, does not raise the same ethical concerns, and may well be worth implementing.

Other Issues

There are, of course, other substantial issues raised by organ donation which are outside the scope of this paper. In particular, the notion of organ donation as a "gift" versus the taking of organs, matters such as the social duty to donate, the question of "possession" of organs, their intimate connection with human beings as embodied selves, and the changed relationship after death are raised particularly by the suggestion of an "opting-out" policy. Neither will I consider living donations nor the issues raised by commerce involving human body parts. These are issues that could be discussed at another time.

It is important to note that the term "donor family" is inaccurate since it misleadingly

suggests a unified entity. Partners and family members of potential donors are individuals with varying degrees of closeness to the potential donor. They differ in their grief and coping skills. Their attitudes and beliefs about death, the person and organ donation vary. In view of this diversity, it is better to speak of "members of the donor's family" rather than of a "donor family".

The Spanish System: "Hot Pursuit"

Since 1989, organ transplantation in Spain has been coordinated by a central system, the Spanish Transplant Coordinator's Network (ONT) based in Madrid, which allows local autonomy to each of Spain's seventeen regions.² The fundamental priority of the scheme is organ procurement. There is an efficient central system of data collection and management and the central body coordinates all aspects of organ procurement, transplantation and follow-up of donors' family members. Organ donation has been professionalised at all levels. There is an emphasis on education of transplantation staff, the identification of potential donors and the approach to families of potential donors. The Spanish Transplant Coordinators' Network (ONT) runs courses for coordinators and programmes for other health professionals. These programmes are aimed at increasing donation rates, for example by (a) considering older or "marginal" patients as potential donors, and (b) improving the support and counselling

Current Australian Practice

The practice in Australia could be summarised as follows. After two specialists, neither of whom may be part of the transplant team, have diagnosed a potential donor as dead in accordance with the destruction of brain function criterion, his or her family is consulted. Most commonly, it will be an Intensive Care Specialist or a Transplant Coordinator who discusses organ donation with the family. Ideally, some time will elapse between telling the family about the diagnosis of death and asking them to consider organ donation. If the potential donor's wishes are known (from documentation such as a driver's licence or a Donor Card, for example) then the family members may or may not be asked if they have any objection to organ donation. If the potential donor's wishes are not known, then the family members may be asked if they would give

permission for organ donation. In fact, the law in the various Australian states does not require consent of the family in this situation. The law states that the "senior next of kin" must be consulted to establish whether the potential donor had expressed any objection to organ donation during his or her life.¹ The law recognises that the family is acting on behalf of the potential donor. Of course, relatives find this a difficult decision to make, and it would be hard to imagine more difficult circumstances for decision making than those around potential organ donation. So, the family's permission to proceed is sought and it is unlikely that a surgeon would go ahead with organ procurement over the objections of the closest next of kin.

1 J.F. Thompson, *et al.*, "Can cadaveric donation rates be improved?" in *Anaesthesia and Intensive Care*, 1995, 23: 99-102.

of the families of donors. A secondary benefit of this is increased acceptance of donation in the community.

Compared to Spain, Australia has a much less centralised system. Central registers of recipients for particular organs are kept in different states, and interstate cooperation is organised through donor transplant coordinators. Recipient transplant coordinators work in individual hospitals. Unlike the Spanish situation, transplant coordinators do not assess patients outside Intensive Care Units to consider their suitability for organ donation. It would be unusual in Australia to transfer a patient to intensive care for ventilation unless that treatment was for the direct benefit of the individual. While not illegal, as it is in Britain,³ it is not currently the practice to ventilate a dying patient with no other end in sight except potential organ procurement.

Spain also has an efficient system of media management. This counters the dramatic effect that negative media reports have on the number of donated organs. There is a twenty-four hour telephone service to answer questions about transplantation. This is heavily used by the media and by the public. Attention has been devoted to distributing information and establishing good communications with the media. Media reporting serves mainly to provide the public with information about organ transplantation in general. There is a deliberate policy of responding swiftly to negative media reports. These responses come from the top and deal with contentious issues, like brain death and reports of trafficking in organs as a counter to sensational misreporting. In Australia, the media may be less compliant, with a penchant for sensational stories, but the benefit of this could be a more critical and thoughtful coverage of the relevant public health issues.

The success of the Spanish system has been outstanding. Between 1989 and 1994, the donor rate rose from 14.3 per million population (pmp) to 25 pmp. Spain does have a higher road toll than Australia so the pool of potential donors is much larger. However, the increase in donation rate was achieved despite a 40%

decrease in road fatalities since 1992.⁴ The waiting time for heart transplants is one month. Several features of the Spanish system must be noted however. ONT's success is due in part to targeting of education to health professionals, with a focus on overcoming obstacles to organ donation. The Spanish system is also funded, per capita, at ten times the rate provided in Australia to The Australian Coordinating Committee on Organ Registries and Donation (ACCORD). Success requires adequate funding.⁵

Focus on the Family

The Spanish model focuses on the family of the potential donor. Family consent is sought, and objections are not overridden. Information-giving and counselling are emphasised at the time of the organ donation as well as later. The majority of family members who express reservations will decide to agree to donation, which raises the question of whether they experienced information exchange, persuasion or coercion at the interviews. Follow-up studies of families show little regret about the decision. This suggests that consent was free rather than coerced. But the concern remains. There are also potential conflicts of interests. Spanish transplant coordinators declare brain death, obtain consent and have as a goal the maximisation of organ procurement rates. The general practice in Australia of having a clear boundary between those declaring brain death and the transplant team avoids doubt about possible conflicts of interest.

Overall, a modified version of the Spanish scheme could be devised which raises no greater ethical issues as regards the family than does the current practice in Australia. Could the same be said for proposed "opting-out" schemes?

"Opting-in" or "Opting-out"

In Australia, we assume that it is reasonable to take organs from the body of a dead person provided either that the person consented prior to his or her death or that the person's family gives consent *on his or her behalf* after the person's death. The basis of this approach is said to be respect for persons, a respect based on human dignity, autonomy or self-determination and the intrinsic value of human life. In most countries

one of two general approaches to consent to organ donation prevails. In some countries there is "presumptive consent". It is assumed that all citizens agree to donation of their organs after death, unless they explicitly refuse. In the absence of explicit refusal, or "opting-out", a person's organs may be removed for donation after he or she dies without further questions of consent being raised. This is the practice in Belgium and France for example. In Australia, the United States and most common law countries, the general approach might be called "opting-in". The donation of organs requires explicit donor and family consent.⁶

In practice there is usually a combined approach. For example, in France, where "opting-out" is legislated, families are usually consulted prior to organ procurement, and serious family objections are respected. In Australia, people may opt-in by ticking the box on their driver's licence. If they have not done so their family may be consulted and given the opportunity to consent on their behalf (or alternatively to "opt-out"). The limitations imposed by shortages of donor organs ensures that pressure to consider a definite "opting out" policy continues at a low level in the transplant community, as does resistance to such pressure.

Proponents of an "opting-out" policy argue from a "respect for life" position – focusing on the life of the potential recipient, and the ethical duty to improve the efficiency of organ procurement in Australia. It is argued that this policy would ensure that no potential donor organs are wasted, and that the autonomy of potential donors is not infringed. The potential donor's duty to the community is stressed. People would have the right to refuse consent, perhaps by having their name recorded on a register of those opposed to organ donation.

Unfortunately such a scheme gives the illusion of respect for autonomy while obscuring the fact of real coercion. Respect for autonomy needs free and informed consent. An "opting-out" policy assumes that every person is fully informed, and has made a conscious decision about organ donation. Considerable amounts of money would need to be spent informing the public of their right to refuse to donate organs,

and making the registering of refusal to donate accessible to all. Currently, very little money is spent educating the public about transplantation and encouraging them to be donors. There would be little incentive to spend larger amounts of money to make it possible for people to refuse to be a donor.

If there is no practical likelihood that all members of the population could be given the option of refusing to donate organs, there is only pseudo-consent. In effect an "opting-out" policy becomes a front for ensuring that most people will become potential donors despite the likelihood that at least some will be opposed to organ donation. This would be a travesty of respect for the individual's right to be self-determining.

Such a system would also diminish the role of family members at the time when organ donation is being considered. There are some who would see this as a good thing because it removes the opportunity of family members to frustrate organ procurement. But such an attitude misunderstands the role of the family in the organ donation setting. It is also pastorally insensitive.

The Role of the Family

The notion of consent, or at least lack of objection, is embodied in the law and practice of organ donation in Australia. Although there is no requirement for free and informed consent as there is for other medical procedures, it is made real in good practice.⁷ If people wish to donate their organs after death, it is our duty to respect those wishes, as part of our duty to respect the person's autonomy and human dignity. And if people are opposed to having their organs used in this way, it is important to respect that choice for the same reasons.

What is the role of the family members in this situation? First it needs to be said that since the family does not own the deceased person's organs they cannot really be said to donate them. The notion of "consent" here is not straightforward either. The family members are in a situation of sudden and spectacular distress. They will be flooded with information, and may

find it difficult to accept a diagnosis of death, in the face of the evidence of their eyes, when they see the patient's warm, pink body attached to a ventilator. Do the conditions exist for them to make "fully informed and free" decisions?

The Family and Organ Donation

How are we to understand the role of the family in this situation? Family members have three roles with respect to potential organ donation:

- First, the family members act as the **custodian** of the wishes of the dead. They act out of fidelity to the one they loved. Whether the person previously desired to become an organ donor, or was opposed to the idea, the relatives ensure that the person's wishes are carried out to the extent that they are known. This is an expression of their respect for the person who has died. If they know the dead person's wishes most relatives will not object to organ donation even if it is contrary to their personal beliefs.
- The family members' second role is to **substantiate** the decision of the potential donor. If there is no documentation of a person's prior choice, the family members are consulted because they may know what the person wanted, perhaps because of past discussion. The family members are here a source of evidence of a past choice. Even in cases where there is a record of a past choice, the family members are still consulted because they may know whether the person changed his or her mind, say in the years since ticking the box on the driver's licence.
- Finally, the family members may act as a **surrogate decision makers**. If a person's wishes were not articulated before his or her death, the family members are asked to assess whether the person would have wanted to donate his or her organs in this situation. We often speak of the relatives "consenting" to organ donation, but in a sense the right to consent is not theirs. They are calling on their knowledge of the dead person's beliefs, attitudes and character - their knowledge of what kind

of person he or she was - to assess what decision that person would have been likely to make in this situation. The family members here make a decision "on behalf of" the one now dead. Their unique knowledge of that person in life places them in a position to make this assessment.

In addition to their responsibilities to respect the interests of the person who has died, family members also have legitimate needs, interests and responsibilities. They grieve and they have a duty to take care of themselves. They make their own call on the staff who have been involved in caring for the potential donor. In particular, they need information, practical support, counselling and follow-up.

Is There a Right to Refuse?

Sometimes the choice of the next of kin will conflict with the previously expressed wishes of the potential donor. How do we resolve these conflicts? Giving information may help. If a family member is opposed to organ donation, and the potential donor had previously expressed a wish to donate, the family can be told what the person's wishes were, and that the responsibility for the decision does not rest with the family member.

When the next of kin is determinedly opposed to the potential donor's choice to donate organs, doctors usually decide to respect the wishes of the relative. Is this a violation of the autonomy of the potential donor? It is reasonable to give precedence to the family member's choice for three reasons:

- A person's decisions in life about organ donation are made without full information about how those decisions will affect his or her close relatives. /for example, the person may not foresee the degree of distress caused by the prospect of organ donation when it comes to the crunch. If the potential donor is the kind of person who considered giving his or her organs to help a stranger, it is reasonable to assume that he or she is the kind of person who might revise the decision if it would be for some one he or she loved.

- We respect a person's right to make decisions and to put those decisions into practice. We ordinarily understand that the right to be self-determining is limited by other people's rights not to be harmed by our actions. The potential donor's right to choose organ donation is balanced against the risk of harm to close family members.
- The doctor's duty of care to the patient is altered after death by conflicting duties to others. The person who made the decision to donate organs is now dead, while the family members are not. The doctor has a duty to them not to compromise their grieving process.

The doctor has duties (a) to the dead person - to respect his or her wishes and (b) to potential recipients - to maximise donation rates. These duties may conflict with the duty to the family members. The duties may be less binding if the relative's risk of harm from proceeding is high. In addition, organ transplantation programmes require the consent of society since funding comes from tax revenue and the organs are available only if individuals give consent to use of their organs. Increasing the trauma for relatives, in the already stressful situation of potential donation, harms the long term interests of transplantation programmes.

Conclusions

There are obvious grounds for wanting to increase organ donation rates in Australia. A recent study of potential organ donors in Australian hospitals found that the major obstacles to organ donation include "unsuccessful resuscitation" (i.e. the patient died before organ procurement was feasible) in 30% of cases, family refusal in 34% of cases and failure to identify and organise ventilatory support in 36% of cases."

This paper has considered two proposals aimed at increasing the donor rate. On the one hand it is hard to see how changing to an "opting-out" policy would remove these obstacles to donation. There would be a substantial ethical cost with such a proposal if

respect for donor autonomy was sacrificed. Further, there is the risk of increased community opposition to organ donation if people feel they are being coerced or if a change in policy results in the relatives of potential donors being scandalised or badly treated in the event of an organ donation procedure where consent has not been established to their satisfaction. To justify a change of policy in favour of "opting-out" there would need to be demonstrated gain from a change to the system to set against this risk and to set against the potential ethical cost.

On the other hand, a version of the Spanish system (modified for the Australian context), does not inherently have those risks. It also has demonstrable benefits (at least in Spain). Because the Spanish system focuses on the family and on procurement of consent, it has two intrinsic advantages. First, the approach does not hinder, and may enhance, counselling and support of the grieving members of the donor's or potential donor's family. Second, it respects the social and ethical role of the family in the situation of organ procurement. Therefore, the South Australian trial of a scheme based on the Spanish System seems very reasonable.

Notes

- 1 J.F. Thompson, *et al.*, "The identification of potential cadaveric organ donors", *Anaesthesia and Intensive Care*, 1995, 23: 75-80.
- 2 This section is a brief summary of an article by Paula Boddington, "Organ donation and ethics - Could Australia accept the Spanish model of organ donation?" *Monash Bioethics Review*, 1996, 15: 33-43.
- 3 J.F. Thompson, *et al.*, "Can cadaveric donation rates be improved?" *Anaesthesia and Intensive Care*, 1995, 23: 101.
- 4 "Spanish system set for Australian trial" in *Accord*, September 1995, 12: 1.
- 5 Boddington, *op cit.*, pp. 36-42.
- 6 E.W. Keyserlingk, "Human dignity and donor altruism", in *Transplantation Proceedings*, 1990, 22: 1005-1006.
- 7 Boddington, *op cit.*, p. 37.
- 8 Thompson, *et al.*, "The identification of potential cadaveric organ donors", *Anaesthesia and Intensive Care*, 1995, 23: 75.

Euthanasia — clarifying the issues

The refusal of life-prolonging treatment

Gerald Gleeson

If it is wrong to request euthanasia, how can it sometimes be right to refuse life-prolonging treatment?

In the current debates about legalising euthanasia it will be crucial for all Australians to reflect on the ethical issues at stake. Among these is the critical distinction between *the request for euthanasia* and *the refusal of life-prolonging treatment*. The Catholic moral tradition holds that the former is always wrong, while the latter may be morally justified.

To see why this is so, we must first recognise that the same outward behaviour may embody utterly different moral intentions. When the nurse turns off a life-support machine and the patient dies soon after, we cannot tell just from observation whether this is euthanasia or whether it is the legitimate cessation of burdensome treatment. Many bio-ethicists claim there is no difference between euthanasia and the legitimate refusal of treatment because both the *outward behaviour* and the final *outcome* may be the same in each case. Others emphasise patient "autonomy" to such an extent that they think that whatever a patient requests is right, simply because the patient requests it. The Catholic moral tradition enables us to understand why both these views are unsatisfactory. What makes human actions right cannot simply be reduced either to just "good outcomes" or to "autonomous decisions".

Ethical rightness depends on both the character of a person's considered decision-making, and on the way his or her decisions are ordered to what is truly good, both for oneself and for those who are affected by one's actions. Life is essential to the good of human existence and so ethical reflection about medical treatments should start from one's *responsibility* to take *reasonable* measures to safeguard one's life and health. Just being alive and healthy is foundational to everything else in life, and so

caring for one's health is a fundamental moral responsibility. Nevertheless, just being alive is not what is most important in life. We praise martyrs, including "volunteers" like Maximilian Kolbe who took the place of a man condemned to death, because we acknowledge that there is a more fundamental responsibility than that of simply preserving one's life.

Responsibility for one's life as a whole

What is this more fundamental responsibility? One's physical life is both valuable in itself and finds its realisation in the service of the many other goods which make up a truly human life: our relationships with others, our intellectual and emotional concerns, our respective vocations and careers, our artistic and recreational endeavours, and—above all—our religious convictions. My fundamental moral responsibility is not to just remain alive, but is to pursue the fully "integral" development of my life in all its aspects.

Many people speak of these varied dimensions of human life in terms of the "quality" of a person's life. This is a misleading notion if it is taken to suggest that a *person's* worth depends chiefly on the way he or she *experiences* life. Talk of "quality" promotes the idea that unless a person's "experience" of life meets a certain standard, his or her "life is no longer worth living". The lives of the handicapped, the lonely, the mentally unstable, the sick and the frail, are most vulnerable to being thought of (by others!) as lacking sufficient "quality" to be worth preserving.

Against this we must affirm that every human being is of inestimable value, regardless of the "quality" of his or her lived-experience

(however that is to be assessed!). It is always wrong to take an innocent person's life because in so doing one destroys the very basis of the person's existence and of all that is valuable in it.

Nonetheless, it is also true that "just staying alive" should not be the supreme value for a human being. The context in which "staying alive" finds its fulfilment is provided by all those other goods mentioned earlier. Because one has a responsibility to pursue one's *integrated fulfilment* as a human being, the responsibility to prolong one's physical existence is not overriding. The measures one takes to prolong one's life should always be "reasonable" — given all the other goods of human living which are at stake.

While there are fairly "objective" medical indications about what would be reasonable and appropriate treatment in most situations, there are also "personal" indications unique to the individual concerned. For example, a man might be struck down by an ailment that could be alleviated were he to move to a different climate, in a distant country, away from family and friends, where he would be unable to speak the language or gain employment. It would not normally be reasonable to expect a person to go to such lengths in order to care responsibly for his health.

Reasonable treatment

For treatment to be reasonable and appropriate, it must be likely to be *effective*, with its benefits *proportionate* to its burdens, with respect to both the patient and the available human and medical resources. In taking "reasonable" measures to care for one's health, a person is not required to do what would be for them "unduly burdensome" or, in older terms, "extraordinary". In refusing such treatment a person's goal or "moral object" is not to remain ill, or to die, but is to forgo something which is not, in the circumstances, obligatory. Moreover, a treatment option that would be burdensome for one patient, might not be for another. There is usually a *range* of reasonable and conscientious judgments that may be made by different patients in similar circumstances.

Consider the case of a man who is left quadriplegic after a diving accident, only able to remain alive with the help of a ventilator to assist his breathing. May he request that the ventilator be removed, knowing that he will die soon after? That, after sufficient time for due consideration, he might forgo this means of prolonging his life, would seem to fall within the bounds of what is reasonable, if that treatment would only offer him unrelievable discomfort, emotional and spiritual barrenness, frustration and boredom. Such burdens might undermine so much else that should contribute to an integrated human life.

Of course, another person in a similar predicament might choose to continue to live on the respirator, in view of his continuing relationships with others, and of his emotional and spiritual resources for dealing with the tragedy that has befallen him. Many people have come to pursue worthwhile and satisfying lives in such conditions. Nonetheless, in some cases like this, the refusal of treatment would not necessarily indicate a failure to preserve one's life when one ought to do so.

The distinction

The request for euthanasia is the request to be killed because life has become a burden. Such a request could never be a reasonable way of caring for one's life, because deliberate killing attacks not only life but also personal existence in all its dimensions. To accede to people's requests for euthanasia is implicitly at least to agree with their judgments that *their lives* are no longer worth living.

The refusal of life-prolonging treatment need only be the request for the cessation of something one is not obliged to do or to undergo. There are limits to what can reasonably be required for the sake of prolonging one's life because just staying alive should not be the overriding value in a person's life. Life is not to be prolonged *at any cost* — not at the cost of one's emotional and spiritual well-being, nor at the cost of impoverishing one's family, nor at the cost of imposing disproportionate burdens on oneself or others. To accede to someone's request that

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Genetics: The Ethical Questions

Keith Joseph

Genetic medicine is at the forefront of medical research today, spurred on by large projects such as the Human Genome Project. This project aims to map the entire genetic sequence of human by the year 2005, and will provide the detailed knowledge of our genetic structure which is necessary for widespread advances in genetic medicine.

Unfortunately, there is widespread misunderstanding of what genetic medicine can achieve, and therefore of the ethical problems that could arise from it. This stems, in part, from public lack of knowledge of genetics and biology, and from the desire of the media to obtain a good story which usually relies on emphasising the positive or the negative attributes of a new technology. Therefore, the popular image of genetic medicine is either one of awe at the brave new age of medical success it heralds, or one of fear of the abuse of genetic medicine in the hands of unscrupulous technocrats.

As usual, the truth lies in between. Genetic medicine does offer the promise of significant advances in diagnosis and treatment of some disorders, but it will not be a universal panacea. It also is open to abuse, and thus there are significant problems that can arise. However, science fiction scenarios in which genetic engineering is used to create a "brave new world" are a little far fetched.

The most immediate area in which genetic medicine can be applied is that of screening for diseases and disorders which are genetic in origin. This can be done either to a foetus, or to a person after birth. In the former, it is usually done with the intention of aborting a foetus with a significant genetic disorder; in the latter, the purpose is to confirm a diagnosis or risk of genetic disorder. Both of these uses lead to major ethical problems.

In the longer term, the technique of genetic manipulation - the alteration of genetic

structures - may become available. There have already been clinical trials using genetic engineering upon humans, with the genes of non-reproductive cells, such as blood cells, being altered. This is known as somatic genetic engineering: the altered genes cannot be passed onto offspring. In the future germ-line genetic engineering will probably become available. In germ-line genetic engineering the genes of reproductive cells are altered, and thus the altered trait can be passed on to offspring. Whilst somatic genetic engineering does give rise to some ethical problems, these are insignificant in comparison to those which germ-line genetic engineering will cause.

The purpose of this paper is to outline these ethical problems, and to give some structure to our approach to these problems. The need to do so is urgent, as we have the opportunity to deal with these problems ahead of the widespread introduction of the new technologies associated with genetic medicine. We have the chance to "get it right".

Ethical Problems associated with Genetic Screening

1. Genetic Screening of Foetuses

The main reason for genetic screening of foetuses is to allow the parents to choose to terminate the pregnancy if the foetus has a genetic disorder. Obviously, the first ethical issue here is that of abortion. The second issue is concerned with the traits we screen for: what disorders are serious enough to warrant considering abortion. A final issue is that of the use of genetic screening for eugenic purposes.

2. Genetic Screening after birth

Genetic screening can be carried out to benefit three basic groups:

- a. *Individuals affected by a genetic disorder.* In this case the screening is intended to confirm whether or not an individual had

a particular disorder, or is predisposed towards a particular disorder. The benefit of such screening can be diagnostic; it may allow better therapeutic or palliative care for the patient; or it may enable prevention of a condition which the individual is genetically predisposed towards.

- b. *The offspring of individuals who carry a genetic trait.* All humans carry recessive genetic traits that may express themselves in their descendants. If they are aware of the potentially deleterious traits that they and their partner have, they may be able to determine whether or not their children are likely to be affected.
- c. *Third parties, such as insurance companies.* Many third parties may have reasonable grounds for wanting access to information about the genetic structures of individuals. For example, law enforcement agencies are now using DNA tests to identify possible criminals. Insurance companies may wish to know if a potential client is carrying genetic traits which could influence their risk.

All of the above categories carry with them significant ethical problems. For example, if an individual has a predisposition towards a certain disorder, is it better for them to know or not to know? Does the screening of genetic traits in potential parents lend itself to the selection of socially desirable traits, or the elimination of socially undesirable traits, rather than the control of genetic disorders? Which third parties should have access to genetic information? Will it result in discrimination against the genetically different? Is it unfair for insurance companies to discriminate on grounds that potential clients cannot control, such as their genetic structure?

3. *Intellectual Property Rights*

An area of increasing legal and moral concern is that of intellectual property rights and genetic information. There are three conflicting ideas here. The first is that people who make a new discovery have the right to materially benefit from that discovery. The second is that information should be freely available, to the benefit of society and science. The third is that

information about humans cannot be "owned" by anyone apart from the individual concerned. These will come into conflict. For example, attempts have been made to patent human gene sequences. If such patents are granted, the persons who discovered them (usually commercial or academic enterprises) will have the right to control, for a certain period, the use of that sequence. This can be quite lucrative, in that pharmaceutical products and diagnostic tests can be produced using such knowledge. However, it restricts other scientists in the use of that knowledge. Additionally, if the sequence has been obtained from an individual or from a small group, then there is the question of the rights of that individual or group: in what sense can someone else be said to "own" their genes?

4. *Summary - Genetic Screening*

All of the above problems arise out of the access to knowledge of the genetic structure of individuals. It is a new problem, in that we are only gaining access to that knowledge now for the first time. The basic ethical questions are these: Who should control that knowledge? What should that knowledge be used for? By thinking about these questions we will go a long way towards resolving some of the moral issues involved.

Ethical Problems associated with Genetic Engineering

1. *Transgenic genetic engineering*

Transgenic genetic engineering is the altering of an organism so that it has the genes of another organism. Modern genetic engineering permits human genes to be added to those of other species, and the genes of other species to be engineered into a human's genetic structure. The addition of human genes to other species has already been done: for example, human insulin, which is administered to insulin-dependent diabetics, is created from genetically engineered bacteria which express the gene for human insulin. The gene for human growth hormone has been inserted into experimental pigs to encourage growth for meat production; and it is proposed to genetically modify pig's hearts with human genes, so that they are suitable for heart transplantation into

humans. Such experimentation can bring significant benefits, as insulin-dependent diabetics will attest. However, in the long term it may cause the species barrier to be questioned, thus undermining the concepts of personhood and humanity.

2. Somatic Genetic Engineering

Even with the best screening programs and diagnosis, our responses to genetic disorders will tend to be palliative or preventative. Genetic engineering offers the possibility of effective treatment. Somatic genetic engineering will allow us to treat individuals. While they will still carry and pass on the genetic trait, it will be possible to prevent its effect on them. Germ-line genetic engineering, in comparison, aims to eliminate the genetic trait altogether.

In many ways, somatic genetic engineering raises problems similar to those raised by organ transplantation. At present somatic genetic engineering is expensive, ineffective, and involves the insertion into a body of organs or cells which are not genetically the same as the host, which can lead to uncertain side effects. However, this has led many commentators to argue that the ethical problems in somatic genetic engineering are essentially the same as those for organ transplantation, and thus it does not raise new ethical issues. However, in its linkage to genetic screening and germ-line genetic engineering, it can be argued that it shares in the problems of those techniques.

3. Germ-line Genetic Engineering

This is the most remote possibility of genetic medicine, but also the most troubling. Our genes, in conjunction with our environment, determine much of who we are. Germ-line engineering thus gives us the ability to influence our descendants in a significant way. This ability to influence our descendants is quite overrated. It is not possible to change a single gene and convert a person into a mindless slave or fearless soldier: most genetic traits involve both a large number of genes, and a particular environment in order for them to operate. For similar reasons, we are unlikely to cure all disease using genetic engineering. The complex relationship between the various genes, and the environment, render this an improbable dream.

Nevertheless, there are a number of genetic traits which are seen as leading to disorder, and which germ-line genetic engineering may be able to eliminate. For example, cystic fibrosis and some rare genetic diseases such as Tay-Sachs disease (which leads to death in the first few years of life) may be amenable to elimination by genetic engineering. More controversially, there are some genetic traits - such as those related to stature or intelligence - which are seen as socially desirable and which parents may seek for their children. This leads onto the problematic area of eugenics, which is the idea that we should encourage the birth of children with desirable genetic traits, and discourage the birth of those with undesirable genetic traits.

Conclusion

Genetic medicine has much to offer, and will be an important part of medical advances in the next decade. However, it will also give rise to major ethical difficulties. Our genetic code is a source of information that we are currently deciphering: the basic issues revolve around the derivation and use of that information. We need to be considering now the ways in which we want to control and manage that information, and the basic ethical principles which will underlie this process.

Euthanasia - clarifying the issues: The refusal of life-prolonging treatment

(contd. from page 8)

treatment be stopped is at most to agree with their judgment that the benefits of prolonging life are disproportionate to the burdens that prolonging life would entail. To appreciate the difference between the *request for euthanasia* and the *request for the cessation of treatment* we must consider each request in the context of the prior responsibility to safeguard one's life and health.

Whereas the choice to kill contradicts this responsibility, the choice to withdraw or withhold treatment respects the twofold truth that life is always a good to be respected, even though one's duty to prolong one's life is not absolute, for it must be governed by one's higher responsibility for the integral good of one's life as a whole.

NOTEBOOK

Studies in Health Care Ethics

Ethics in Health Care or Bioethics is increasingly important in society, in health care institutions and in professional practice. Australian Catholic University offers two programmes in Health Care Ethics:

Graduate Certificate in Applied Ethics (Health Care)

- introductory studies by coursework
- one semester full-time study or one year part-time study

Admission Criteria

Graduate Certificate: any undergraduate degree or professional qualification with experience

Master of Arts: professional qualification with experience; or suitable undergraduate degree in Philosophy or Theology

To Whom Might the Course be Valuable?

Each course will be of value to professional and other citizens interested in the moral and social significance of ethical issues in health care. Each course can be of special value to particular people, such as members of institutional ethics committees.

Master of Arts in Applied Ethics (Health Care)

- advanced studies by coursework, with the opportunity for research
- one year full-time study or two years part-time study

Modes of Offering

Both courses are scheduled by negotiation with students. The aim is for maximal flexibility to fit in with students' busy lives.

For Further Information Contact:

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Advanced Bioethics Course, 1996

The Advanced Bioethics Course for 1996 will focus on the issue of Genetics. However, changes have been made to the date and to the venue which were given in the December 1995 edition of *Bioethics Outlook*. The Course will now be held in the Auditorium of the Garvan Institute of Medical Research, 384 Victoria Street, Darlinghurst. The proposed date is Friday, 25 October.

An introductory session on genetics will be followed by sessions on the human genome project, genetic screening and genetic engineering. The concluding session of the Course will take the form of a hypothetical which will bring together many of the ethical issues in genetics, including those which will have been raised during the previous sessions.

For further information please contact Barbara Reen at the John Plunkett Centre for Ethics on (02) 361 2869.

Bioethics Outlook is a quarterly publication of the John Plunkett Centre for Ethics in Health Care, a Research Centre of Australian Catholic University and St Vincent's Hospital, Sydney.

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Editor: Gerald Gleeson Layout: Barbara Reen

Subscription is \$50 (Institutions), \$35 (Individuals) and \$15 (Students or Pensioners).

John Plunkett Centre for Ethics in Health Care, St Vincent's Hospital, Victoria Street, Darlinghurst NSW
2010 AUSTRALIA

ISSN 1037-6410