ETHICS & MEDICINE

AN INTERNATIONAL CHRISTIAN PERSPECTIVE ON BIOETHICS

Vol 14:3 1998
ISSN 0226–688X

Journal of
The Center for Biothics and Human Dignity, Bannockburn, Illinois, USA
The Centre for Biothics and Public Policy, London, UK
The Prof. G.A. Lindeboom Instituut, Ede, Netherlands

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This journal is abstracted in *Religious and Theological Abstracts*, 121 South College Street (PO Box 215), Myerstown, PA 17067. USA
It is also included in *religion index one: Periodicals (RIO)*.
All book reviews are indexed in: *Index to book reviews in religion* (IBBR). Both are available from: American Theological Library Association, 820 Church Street, Evanston IL 60201-5613.
E-mail: atla@atla.com
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Microform

This journal is available on Microform from UMI 300 North Zeeb Road, PO Box 1346, Ann Arbor MI 48106-1346 USA.
Tel: (313) 761-4700

Subscription Rates

Ethics and Medicine is published by Paternoster Periodicals three times yearly. Subscription rates are as follows:

1 year
UK £12.60 USA $33.00 Overseas £13.50

2 years or more, per year
UK £11.35 USA $29.70 Overseas £12.15
Cheques (made payable to 'Paternoster Periodicals') should be sent to Paternoster Periodicals, P.O. Box 300, Carlisle, Cumbria, UK, CA3 0QS.
Tel: 01228-512512 Fax: 01228-514949 Email: pp@stl.org

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Typeset by WestKey Limited, Falmouth, Cornwall.
Printed in Great Britain for Paternoster Periodicals, P.O. Box 300, Carlisle, Cumbria, UK, CA3 0QS by BPC Wheatons Ltd, Exeter.
ISSN: 0226-688X

Ethics & Medicine (1998) **14:3**, 65 0226–688X

C. Ben Mitchell, PhD, Editor

Viagra and the Future of Medicine

Keywords: impotence, therapy, enhancement

If there are any lessons to be drawn from the recent cultural experiment with Viagra, one lesson is that it will be increasingly difficult to draw the line between enhancement technologies and therapeutic treatments. To date, it appears that the majority of Viagra users in the United States use the pharmaceutical recreationally. To make such an assertion, however, is to beg a more interesting question philosophically. Is the treatment of impotence an enhancement or therapy? Certainly human beings are sexual beings. From the beginning God made us so. The 'one flesh' union between a man and a woman far exceeds sexual union, but it does include it. At the same time it is clear that, to turn a phrase, we do not live by sex alone. That is to say, impotence does not make us less than human. We can (however great a surprise this may be to some) live without sexual intercourse.

While there have been many warnings about the so-called recreational use of Viagra, one man's recreation is another man's therapy. Viagra, and its certain-to-be-developed cousins, seems to be an effective treatment for certain forms of impotence. United States health insurers are having an extraordinarily difficult time convincing the public that one pill per week is therapeutic while more than one pill per week is, shall we say, an unnecessary enhancement.

Translating the Viagra revolution to the discussion of future genetic technologies presents us with quite a set of dilemmas. Which treatment modalities are therapeutic and which are enhancement? Once a procedure or drug is available for a real or perceived problem, can its use be limited in any meaningful way? Treatment for cystic fibrosis seems clearly to be therapeutic. A genetic treatment to ameliorate or cure a disease seems highly warranted. But what about the administration of human growth hormone to treat a child whose adult height might be significantly less than average? Is that a treatment or an enhancement? And who pays for it?

Now these are not new questions. But the response to Viagra clearly calls into question our ability to think carefully about the enhancement/therapy dyad. Once the drug was available, thousands of prescriptions per day were written. Even though contra-indicated in some cases, men pop the pills with abandon. Some women are clamouring for their own version of the drug. Imagine the response to a genetic 'treatment' which might yield ten more IQ points for a student preparing for her graduate school admissions exams. Or, what about a genetic cure for male pattern baldness?

In a culture which is so self-absorbed can we really hold the therapeutic line? Will we be able to make any meaningful distinctions between treatments for diseases and modalities for, shall we say, the aesthetically challenged?

One of the challenges of the twenty-first century will be to help 'consumers' of medicine think carefully about these issues. If the next century will indeed be the 'Biotech Century,' we will have to reckon with the enhancement/therapy dyad in ever more cases. Without a rather robust ethic we are unlikely to make the right choices.

Christian Hippocratism offers not only a way into the discussion, but help in framing and addressing the issues. As has been suggested before in these pages, biblical anthropology and the goals of medicine coincide in Christian Hippocratism. While we must be somewhat modest in our proposals for the future, we nonetheless must be confident of the foundation upon which we stand.

We will continue, if the Lord wills, our cultural discussion of the difference between therapy and enhancement. May we learn to be vigilant and ever more thoughtful in the light of recent experience with Viagra.

Apology

The Editor and Publishers wish to apologise for the late delivery of this issue.

Ethics & Medicine (1998) **14:3**, 66–69 0226–688X

Carl F. H. Henry, Ph.D.

Commentary

Keywords: abortion, euthanasia, martyrdom, divine sovereignty, suffering, the cross, compassion, judgement, resurrection

Reflections on Death and Suicide

When and how to *die* interests the present generation more than how to *live*. This shift of perspective, or exchange of priorities, has immense consequences. For it has little to do with Christian emphasis on an afterlife and on a future judgement. It is not the pangs of hell that secular contemporaries fear. Rather, it is crippling arthritis, stroke-induced confinement, or surrender of the self to the deterioration of Alzheimer's disease.

Medical debate over moral priorities is moving beyond its major concentration on abortion to focus also on the propriety of euthanasia and suicide. Former United States surgeon general, C. Everett Koop, warns that, in the aftermath of a readiness to kill the unwanted fetus, the ruling culture is increasingly disposed to kill the suffering self as well.

Questioning the sanctity of human life prepared the way for a readiness to terminate unwanted fetal existence. Next came acceptance of voluntary euthanasia, and now a growing welcome is accorded to involuntary euthanasia also. More and more commentators legitimate both taking one's own life and physician-assisted suicide. What is compassionate, some ask, about postponing human death in an age in which the intermediary triumphs of medical science unintentionally doom us to die of more violent diseases? 'Give me liberty or give me death', as one wit remarks, now associates liberty mainly with the absence of pain. Contemporary culture fosters a cynical mood, one promotive of frontier reflection on suicide, self-advanced or physician-assisted.

The irony of such contemplation of suicide—cases of which in the United States now annually outnumber instances of murder—is their occurrence in a nation where human life has presumably become more congenial than almost anywhere else on earth. Sooner or later a merely utilitarian life-view asks whether one's survival contributes to society, and whether severe pain may not best be conquered by the elimination of the sufferer. Is humanity itself extinguished when humans suffer intense and almost unbearable pain?

The book of Job affirms that God uses affliction to bring spiritual life to maturity. Much scriptural teaching states that suffering can have a constructive rather than a deleterious role (cf. Rom. 5:3–5; 1 Pet. 1:6–9; 2 Cor. 4:1–7).

Especially confusing is a current tendency to equate suicide with martyrdom, despite the striking differences between them. Suicide seeks to free the self from answerability to divine sovereignty, and affirms personal independence. Martyrdom exalts divine sovereignty over against ingrained human preference. Darrell Amundsen depicts martyrdom as the ultimate act of sacrifice for one's beliefs, whereas suicide is an ultimate attempt to escape from suffering. To view suicide and martyrdom as equivalent acts involves a serious misunderstanding of Christian theology, philosophy and history.

Christianity notably opposed the Hindu practice of *suttee* (the self-cremation of widows who threw themselves alive on the funeral pyre of deceased husbands) and the Japanese ritual of *hara kiri* (the self-disembowelment of high-ranking persons seeking to escape public disgrace).

The 20th century has witnessed the martyrdom of more devout Christians than in all the intervening centuries since the crucifixion of Jesus, including mass murders of Christ's followers by hostile Muslims. By the quality of their lives Christians have rebuked the offended pagans. During the apostolic age, and prior to that in the ancient Hebrew prophetic era, and in the intervening centuries since then, a multitude of Yahweh's people have shown the pagan world both how to live and how to die.

Many who contemplate suicide as a hopeful way of well-being have never really learned how to live, let alone how to die. Not a few have used chemical addiction as an avenue to spiritual vitality. Others are mentally confused. Many are ignorant of Scripture.

Does the fact that suicide is consentual establish its legitimacy? Are not many horrendous crimes consentual? Is taking one's own life as morally wrong as taking the life of another person?

That people sometimes want to die need not in itself be wicked. The apostle Paul declared that to be with Christ is 'far better' than this-worldly existence. To be in the eternal home that Jesus prepares for his pilgrim followers can indeed be the fulfilment of life's most spiritual longings.

Yet escape from this present life can be improperly motivated. Although death is gain for Paul, he declares that the Lord can nonetheless stipulate a more necessary alternative (Phil. 1:24). Death is gain, yet the choice to remain may be preferable. God placed us on this planet with distinctive gifts and different burdens for engagement in a global mission to promote justice and redemption. To seek flight to the world to come can comprise a neglect of the religious and moral duties that God entrusts to us.

Despite overwhelming pain, the gifted British Bible expositor D. Martyn Lloyd-Jones, although trained as a medical specialist, refused to seek the relief of pain-suppressing drugs lest he avoid lessons that God's providence would inculcate.

Is it therefore wrong to enlist medical technology in the hope of the discovery of a superior means of containing pain, suffering and grief?

Much of western society pursues the illusion that its technological genius can manipulate and control every phase of human life, suffering and death included. It seeks to remove all limits on human nature and all pain from human existence. Its theologians speak eagerly of the living God's suffering while they seek aggressively to remove suffering from human existence. Even secular distaste for the doctrine of hell is not unrelated to the confident expectation that humans will somehow eliminate all suffering.

Pain is indeed a temporal phenomenon. Yet it can serve as a warning signal that contributes to healing. God has in view the eclipse of pain, suffering, and death in the coming kingdom of heaven (Rev. 21:4). But secular society would banish it from planet Earth, whatever its contributory causes.

Is social policy a definitive referent for evaluating the practice of suicide and of euthanasia? Will euthanasia be considered obligatory if one can no longer contribute constructively to the common good, or if one is smitten by a presently incurable disease? Is economic necessity the equivalent of ethical justifiability? Are seriously disabled persons, or those imposing a financial burden on the community, to be considered—as some would have it—'front-line expendable'? Is it a spiritual obligation or rather a deplorable crime to hasten the death of the terminally ill?

Not all pain is physical. Are the sorrow that suicide inflicts on surviving family members, or the stress it imposes on vocational associates, to be regarded as irrelevant? Suicide can in fact be rendered an appealing option through the false premise that it terminates all suffering, a premise that neglects the fact of one's answerability in the life to come for deeds performed during one's earthly existence.

Does the circumstance that a physical or other professional specialist prescribes contributory medication or withdraws life-sustaining treatment make the act less culpable? If we accept medical technology when it prolongs life, why not accept it when we think it best to shorten or interrupt life? Should we not stop delaying inevitable death?

Is suicide then a human right? If so, does not the exercise of such a right enhance human dignity? And is human dignity not then presumably attested by self-extinction? Is it enough to contend that the suicidal expression of self-determination confirms one's nobility and worth? A. A. Howsepian has commented pointedly that 'one cannot promote one's own dignity by destroying oneself' (*Suicide: A Christian Response*, Demy and Stewart, eds., Kregel, 1998, p. 310).

Does the patient then not have a right to decline treatment that accelerates death? Has the patient an absolute right of self-determination except as God intervenes? Can national or regional political determination (that is, majority opinion) adequately deem suicide to be legal or illegal, moral or immoral?

Is the deepest point at issue concerning the suicidal extinction of life not a tolerable endurance of pain and suffering, but rather the personal worth of a bearer of the image of God? If, as the Bible affirms, life is a divine gift, is not the deliberate destruction of life an affront to God in the face of a human obligation to preserve life for the worship, service and glory of the Creator (and not simply for the common good)?

When God extends individual survival even for a span of days amid life-threatening affliction, does he not provide the afflicted with an added opportunity to 'get one's house in order' in final preparation for the life to come? That God routinely hides from us the day and hour of our death is in fact a matter of divine benevolence. Human self-determination of the year, day, and moment of our personal death may yet be seen less as a provision of helpful information than as a spectre that cheats us of a death shaped by divine providence.

If suicide is acceptable one can hardly oppose physician-assisted suicide when all remedial treatment fails and suffering borders on the intolerable. The hastening of death is welcomed when ongoing life seems meaningless. Does not the alternative involve a needless waste of medical resources and of expensive technology? Or does physician-assisted suicide enlist the medical profession in counteraction to its intrinsic purpose, that of preserving life? Does it not circumvent the aim of medicine, which is to promote life, not to terminate it?

What does Scripture say? The Bible presents a category of evils to which suicide logically belongs but it does not expressly prohibit suicide. Many important affirmations—not least of all the doctrine of the Trinity—likewise are only implicitly stated in Scripture. There are only a half dozen or so references to suicide, and most of these serve only to report historically factual events rather than to focus on the issue of the moral legitimacy of suicide. But one is the commandment 'Thou shalt not kill', although its relevance is debateable.

Do Jesus's person and work illumine the matter? His death differs notably from suicide, from the death of the saints in general, and from martyrdom. There was no absolute necessity for him to undergo the ultimate loss of human life. His life and death were and are substitutionary. The connection between sin and death is in his case not causal ('The wages of sin is death', Rom. 6:23) but rather is delegated and imputed.

We may ask nonetheless what light, if any, he casts on the problem of pain, suffering and death. Jesus did not live a painless existence, as we are reminded by his piercing cry on the cross: 'My God, my God, why have you forsaken me?' The Apostles' Creed affirms that he 'suffered under Pontius Pilate'. When amid the pangs of crucifixion he cried out, 'My God . . . why have you abandoned me?' (Matt. 22:46) he signalled at the same time the climax of the atonement.

There is no recorded instance of Jesus, being ill or unwell, although he was on occasion intensely weary and exhausted. In any event Jesus never complained of pain, though he responded compassionately to the pain and plight of others. Even on Golgotha Jesus engaged in empathetic conversation with the two criminals being executed with him (Lk. 23:39 ff.), and promised paradise to the contrite one. Not all suffering involves physical pain; the deepest anguish is often mental and spiritual, as when Jesus faced betrayal by Judas and when he prayed to the Father to forgive his executors.

God is not absent from the human experience of pain. He

is not an omnipotent and unmoved onlooker; rather, whatever he does or does not do is for the good of the penitent. For those who are on speaking terms with God pain does not occur in a context of hopelessness.

Jesus was not, however, a death-assisting Great Physician in the contemporary sense. Nor did he rush to sustain human life under all circumstances. When life-threatening illness smote his friend Lazarus, Jesus did not hasten to his side, either to cure him or to facilitate his death. Jesus emphasized rather that Lazarus's death was for God's glory; it would ultimately be seen to display God's governance and overarching control. Even beyond this earthly life Lazarus' fortunes would be seen to lie within Jesus' purpose and power.

Yet Jesus healed throngs of the sick, afflicted, and dying. He did not heal all, but his many healings were symbolic of future human resurrection. Nor did Jesus heal the sick on the premise that life on earth is ideally unending. We read in Matthew 5:29 that large crowds approached him escorting the lame, the blind, the crippled, the dumb, and many other afflicted persons who were placed at Jesus's feet, and that Jesus healed them. Jesus's premise was not the recent modern emphasis on the healing power of truth or of music, but rather an emphasis on the healing power of God, which he affirmed and manifested.

Christians have been distinguished by their concern and care for the sick, even for those whose relatives considered them hopeless and abandoned them to die. Christian compassion toward the sick and dying issued in worldwide establishment of clinics, hospitals and other care facilities. They were not caught up in any supposedly merciful effort to hasten the death of the terminally ill, but rather sought to preserve life and to promote recovery.

The endurance of suffering was a distinctive Christian virtue. One will not find in patristic texts any reference to suicide as a desirable escape from suffering and pain. All life's experiences are subsumed under belief in God's sovereignty and goodness to the penitent. The Christian is confident that the coming kingdom of God will put an end to the pain and suffering of God's people.

All Adam's offspring cope with death as the consequence of their fallen and sinful condition. The value of human life is not intrinsic, but derives rather from the fact that humans bear the image of God by divine creation and preservation. Human life is the gift of God whose image humanity bears. Both in life and in death we are the Lord's who made and bought us. Life is a temporary gift that the Creator can withdraw. Neither is human life to be considered merely a means to an end. The death of the godly is precious in God's sight (Ps. 116:15).

Some ancient Greek philosophers affirmed the final perishability of the body and the immortality of the human soul. But Christianity affirmed that humans live on a time line between the Adamic fall and humanity's final judgement, involving resurrection to an eternal destiny.

The twentieth century has refocused the discussion of life mainly in terms of an avoidance of death. The striking exception was abortion and a civilized society's unprecedented slaughter of fetal life. Now the focus is on termination of the life of the senescent.

The naturalistic outlook has in recent generations cancelled the ancient Greek belief that a human soul-aspect is imperishable. Instead, the contemporary outlook contemplates death not only as the final end of personal existence, but as a possibility and prospect that hangs over all of life and reality. Death cancels our relationship to phenomena, to things and animals, while any spiritual relationship to God and the noumenal is dismissed in advance as problematical and presumptive.

In the biblical view eternal life is not merely a matter of enduring personal survival; it is a quality of life fit for eternity. Eternal life is life regenerated by the Holy Spirit for fellowship with God. The natural man does not possess it. Yet it confronts the unregenerate sinner as a divine imperative. New spiritual birth in this life is every sinner's indispensable necessity.

Death, moreover, is not merely a biological unavoidability or natural event. It presupposes moral judgement. The apostle Paul describes death as 'the wages of sin' (Rom. 6:23). This emphasises the fact that we are responsible persons. The creation account echoes the verdict 'to dust thou shalt return' (Gen. 3:19). Death is not merely a normal event in human life, a negative cardiogram or a curve that signals a limit of existence or of survival, not even a brink stipulated by the Creator irrespective of humanity's relationship to the good. It is, as David Dockery has said, the instrument God uses to usher believers into his presence.

Suicide has no Christian legitimacy. It is promoted by bad theology, rests on an alien world-view, and is encouraged by a fallacious life-view. It strips the real world of revelatory reason and of a universal morality. It repudiates faith in God's sovereignty over life and death, and elevates fallen and mutinous humanity as the decisive determinant. It has been hailed as a demonstration that life is ultimately under our own human control, whereas in actuality it reflects life out of ethical control. It is given to serious ethical misjudgements and has costly consequences. Only a flawed morality nurtures suicidal tendencies. Suicide is unable to sever the present life from a final ethical reckoning in the future.

The apostle Paul itemizes an extensive agenda of suffering that punctuated his ministry, which included factors that, according to the modern viewpoint, might have encouraged suicide: advanced age, failing health, and the completion of his missionary task. Yet for Paul not such circumstances but rather God's determination was decisive. Paul refers to a readiness to die prematurely only in the context of a government's right to impose the death penalty upon murderers, and of his willingness to die so that his Hebrew kin might be encouraged to believe in Christ. There is no mention of taking his own life, even though suicide was in his time considered acceptable and was quite common in pagan society.

When Paul affirmed that 'to die is gain' and that 'to depart' and to be with Christ is 'far better', he was surely not affirming that he preferred death by suicide, but only that in this present body we are absent from the Lord (2 Cor. 5:1–10). The longing to be in Christ's intimate presence is hardly a longing to commit suicide. Paul's question, 'What shall I choose?' hardly indicates that he is undecided over whether or not to take his own life. The outcome of his meditation is to leave the alternative of life or death to the Lord; the decision is not in Paul's control but in God's.

Although Scripture does not specifically address the

issue of suicide *per se*, let alone of physician-related suicide, it provides a framework of theology and morality, a world-life view, that enables us to judge it critically. Christians are redeemed by Christ, who enjoins our keeping of the commandments and defines our destiny through a final judgement and universal resurrection of the dead. The promise of eternal life is not merely a matter of endless endurance but of moral and spiritual life fashioned and fitting for eternity. The Christian believers is positioned already in the context of resurrection life. The Christian knows he is not in ultimate control of his body or existence, and waits anticipatively for God, who gave us life, to escort us to his eternal home.

Carl F. H. Henry is best known as the founding editor of *Christianity Today* and author of the monumental six volume work, *God, Revelation, and Authority*. He has been called the dean of evangelical theology. Dr Henry continues his writing and speaking ministry from Watertown, Wisconsin, USA, where he and his wife, Helga, reside.

Ethics & Medicine (1998) **14:3**, 69–72 0226–688X

John S. Grabowski, Ph.D.

Made Not Begotten: A Theological Analysis of Human Cloning

Keywords: Dolly, *imago dei*, human dominion, reproduction, technology, creation, personhood, cloning

The announcement that Scottish scientists successfully cloned a sheep from a single adult cell captured media attention and the popular imagination. But it also rather quickly raised ethical questions in the minds of many, especially given the potential for the use of such technology on human beings. Dolly *deux fois* might be one thing, but the prospect of using the same procedure on the shepherds might make one feel, well—sheepish. Even the popular media found itself pondering the moral implications of assuming divine prerogatives over the disposition of human life.[1]

The reaction of most people to this prospect is a kind of unease or perhaps even revulsion. This is especially the case among people of faith who understand themselves to be creatures subject to a divine Creator. Undoubtedly this reaction is akin to what the German Jesuit theologian Karl Rahner, in arguing against genetic manipulation some thirty years ago, described as 'a humane and Christian "instinct" which can be discovered in the moral field.'[2] However, it seems that it is possible to be more precise in specifying the moral evil entailed in cloning human beings than merely to appeal to such 'instinct.' I contend that the cloning of human beings is morally objectionable because it is dehumanizing or more precisely depersonalizing.

In what follows I will briefly consider the bases for approaching this issue in the understanding of human dominion and human dignity found in the book of Genesis. I will then look more closely at the understanding of human personhood and the impact of cloning technology on it.

Genesis and Human Dominion

Among the most important statements in the Hebrew and Christian scriptures is that humanity, male and female, is created in the image of God (Gen. 1:26–27). The idea of the *imago dei* has a long history of interpretation associated with it. However, the text itself provides an important clue as to how this ought to be understood, in the twice repeated command given by God to humankind to 'have dominion' over the rest of creation (cf. 1:26, 28).[3] In at least one case, this dominion is connected to human reproduction through the shared fertility of male and female (cf. 1:28). Hence through the procreation of new life through sexual union, man and woman exercise dominion over creation in the image of the One who made them.

It is undoubtedly true that at times in western history the idea of dominion has been understood as a kind of *carte blanche* given to humanity for conquest and technological domination of the earth and more recently of ourselves. However, it is equally true that this reading utterly misunderstands the biblical text. If the first creation account sees humanity as standing atop the whole of the created world and capable of relating directly to God, it also sees this dominion as modeled upon and subject to God's own lordship over the earth. The second creation account captures this understanding in its statement that God placed humanity in the garden which he had made 'to cultivate and care for it' (Gen. 2:15). In a word, our dominion over the created world is one of responsible stewardship—not unlimited license.

The fundamental temptation which confronts humanity is precisely to ignore the bounds of our creaturely status and to usurp the prerogatives of the Creator—to attempt to become 'like gods who know what is good and evil' (Gen. 3:5).[4] However, the biblical record makes clear that whenever we thus harken to the voice of the serpent and attempt to usurp the place of the God who lovingly fashioned us, we succeed only in creating disaster, rupturing our relationships to God (cf. Gen. 3:8–10, 23) and one another (cf. Gen. 3:7, 16) and unleashing chaos upon the creation into which we were placed as stewards (cf. Gen. 3:17–19).

This basic pattern applies to the human use of technology as well. Technology can be good; indeed, it can be an expression of our dominion over creation when used according to God's plan and purpose. Thus one can read the flood story of Genesis as a kind of parable concerning 'technology,' in the form of the ark, given by God to Noah to preserve human and animal life on the earth during the deluge (cf. Gen. 6–9). Conversely, technology at the service of human hubris can be utterly destructive as with the abortive attempt to achieve human security without recourse to God through the construction of the tower of Babel which resulted in the fragmentation of human language and relationships (cf. Gen 11:1–9). Hence, technology is morally ambiguous—it can be good as when utilized as the expression of human dominion in the service of God's plan, or it can be evil when utilized by human pride to 'play God.'

Therefore the idea that existing technologies must be used—sometimes called the technological imperative—is false and dangerous. Just because we can do something, does not mean we *ought* to do something. Just because we probably can eliminate human life on this earth through the use of nuclear weapons does not mean that we should. Even more pernicious is the idea that technology creates a kind of irresistible force—we have no choice but to use a technology once it has been created. By this logic the cloning of human beings is inevitable. But technology is not a magic genie beyond our control; it is rather the expression of human intellect and will. The fact that we have not engaged in all out nuclear warfare over the course of the previous decades bears witness to this fact.

Human dominion over creation is a gift from God, but a gift with real limits. When we overstep these bounds and attempt to usurp God's role as Creator with authority over life and death, we disfigure our own creaturely integrity. James Burtchaell, in summarizing the Catholic opposition to certain forms of reproductive technology in the 1987 document *Donum vitae*, states the point clearly:

> The Vatican is too technical, or perhaps too dainty, to state graphically enough that we have been turning procreation into science fiction, and that we have become monsters as a result. A society which venerates Drs. Masters and Johnson and their lab coat lore of orgasm as advisors on the fullness of human sexuality . . . or that orders up children the same way it uses the Land's End catalogue: this is a creature feature that ought not appear even on late Saturday television. Or so I take the Vatican to be telling us.[5]

While the statement was made in regard to in vitro fertilization and artificial insemination, its implications for the cloning of human beings are obvious.

This point accords well with the theology of creation contained within the first creation account. Humanity, while created in the image of God is created on the sixth day with the beasts. Throughout the Bible six is the number of incompletion and imperfection. As such it can denote humanity apart from God. But we are created for the worship of God on the seventh day, the Sabbath. Seven in biblical thought denotes completion, perfection, and is often associated with God himself. Hence creation and humanity is complete in the worship and acknowledgement of the One who made it. When we fail to worship God and set ourselves up in his place, we revert to our origin and become like mere beasts.[6]

A crucial aspect of our dignity as human beings, as opposed to the rest of creation, is our ability to relate directly to God in knowing and worshipping him. For the author of the first creation account it is this that sets us apart from other created things. Animals or the inanimate material creation certainly have an intrinsic worth and as such are entitled to humane treatment. But it is only in the human capacity to worship and acknowledge the God of the universe that creation itself is complete.

Technology, like any other human creation, must reflect and acknowledge this transcendent source of our dignity. When technology breaks free of such moorings and subordinates human dignity to other ends—curiosity, greed, even misplaced compassion—then it becomes dehumanizing and morally evil. Such amoral technology, while still a human artifact, has the power to enslave and dehumanize those who are its objects. The application of cloning technology to human beings offers a number of these kinds of scenarios: clones being grown to produce 'spare parts' for those for whom they have been copied, sports franchises attempting to duplicate celebrated athletes, wealthy individuals who want only the best and brightest to raise as children, or, as the President's National Bioethics Advisory Commission appears to allow, privately funded cloning of human embryos to be used for purposes of experimentation and then eventual destruction.

While there is no irresistible force compelling us to use such technology on human beings, once done there may nevertheless be a certain momentum created by its application which makes it difficult to draw the line at certain kinds of use. Like the sorcerer's apprentice we may unleash forces that we find it difficult to control. To recommend limited applications of this technology may thus set us firmly on the slippery slope.

Persons and Procedures

But there is a still deeper set of theological objections to the application of cloning technology to human beings. We are more than creatures possessed of a real but limited dominion and a specific kind of dignity—we are also persons.

Historical study has shown that the concept of 'person' is one of the unique contributions of the theology of early Christianity to the common patrimony of western thought.[7] In attempting to formulate its faith in a God who was both Three and at the same time utterly one, early Christian

theologians utilized the concepts of 'person' and 'nature' respectively. In this perspective to be a person means to be a unique and unrepeatable individual who exists in and through relation to others. In time this understanding has coloured our understanding of human personhood in various ways.[8]

The application of cloning technology to human beings attacks this understanding of our personhood in at least three distinct ways. First, as Gilbert Meilaender has observed, the language employed by Christians in their creedal confessions of faith describing the procession of the Son from the Father as 'begotten not made.'[9] The language of begetting here is intended to assert an equality of being between the Son and the Father. As Meilaender puts it: 'What we beget is like ourselves. What we make is not; it is the product of our free decision, and its destiny is ours to determine.'[10] Hence in 'making' human beings through cloning we stamp them with an inferior and ultimately subpersonal designation.

Second, to clone a human person mocks his or her uniqueness or unrepeatability by attempting to make a kind of genetic photocopy of that individual. It is true, of course, as some scientists will hasten to point out, that a clone would never exactly replicate the original person because of chance factors and the complex interaction of environment and genetics. Hence a human clone would differ in personality, character, and ability from the person from whom it was made. Theologically, we could be assured that such a clone would have a soul and as such possess dignity and rights. But these factors do not remove the fact that the attempt to produce a genetic replicate of a human individual strikes at the heart of the irreducibility which is constitutive of personhood. As such it can be regarded only as a violation of the dignity of the person.

Third, the application of this technology to human beings undermines the unique relations constitutive of personal identity which come into being when man and woman give themselves to each other in an act which allows them to cooperate with the creative work of God—procreation (cf. Gen. 4:1). That is, at the core of our identity as persons is not only the fact that each of us is a creature and child of God, but the son or daughter of a particular man and woman. Cloning removes the personal relations of parenthood and substitutes the impersonal ones of producer and product.[11] A clone has no parents, only an 'original'. Instead of two sets of chromosomes which form a genetic template for the uniqueness of the person's growth, development, and ultimate independence, there is only a replication of an existing genetic pattern.[12] There is nothing personal in such an origin.

In some ways the application of cloning technology is merely an intensification of the depersonalization of human reproduction already begun in some birth technologies—where the origin of human life is torn from the bodily gift of man and woman to each other in the mystery of love and instead reduced to the outcome of a lab procedure. This is an unworthy beginning for a human person created in the image of God.[13] It is also an overstepping of the bounds of legitimate human dominion.

Such a fundamental depersonalization effected through the misuse of cloning technology in human reproduction has broader social ramifications. It feeds into the loss of reverence for human life and dignity and into the unchained primacy of instrumental reason in our culture.[14] As such it serves to foster what Pope John II has called a 'culture of death.'[15] This culture is one that prizes untrammelled technical efficiency over human life and dignity and the mystery of human personhood created in the image of God. Instrumental reason alone can offer no ultimate argument against human cloning or any other instance of the technological imperative. But when we consider the deeper values of human life and the One who made it, then we find in this possibility once again an echo of the voice of serpent of Genesis: 'you will be like gods'. Such a promise, however, always turns out to be empty—an illusion which promises freedom but delivers only enslavement.

Conclusion

The attempt to genetically manipulate or clone animals for the purpose of producing medicines or food for human use is morally unobjectionable, provided that the animals in question are treated in a humane fashion. The application of the same technology to human beings is morally wrong. Such efforts overstep the limits of human dominion, violate human dignity, and reduce its products to subpersonal status.

A so-called compromise procedure such as allowing only the cloning of embryos which will later be destroyed, only exacerbates the moral evil of this endeavour. This further objectifies human life, making it a disposable commodity which can be used for a period of time and then discarded. To designate and attempt to produce a whole class of human beings to be nothing more than chattels has disturbing precedents in the slave trade of the eighteenth and nineteenth centuries and in the Nazi eugenics programmes earlier this century.

A theological analysis of human cloning which attends to the biblical and theological tradition cannot but view this procedure as both morally evil and socially dangerous. We need not bend our knees to the gods of technology or progress. To attempt to take the disposition of human lives into our hands and so play God is to seize the 'forbidden fruit of biotechnology' or to enlist in the construction of yet another tower to the heavens.[16] Such insubordinations have been tried before with disastrous results. Hopefully, this time we will heed wiser counsel and better angels.

Notes

1. See, for example, Kenneth L. Woodward, 'Today the Sheep . . .' *Newsweek* (March 10, 1997), 60, who writes: 'Perhaps the message of Dolly is that society should reconsider its casual ethical slide toward assuming mastery over human life. Do we really want to play God?'
2. Karl Rahner, 'The Problem of Genetic Manipulation,' in *Theological Investigations*, vol. 9, trans. Graham Harrison (New York Seabury Press, 1972), p. 251.
3. All citations are from the NAB.
4. My translation.
5. James Burtchaell, C.S.C., *The Giving and Taking of Life: Essays Ethical* (Notre Dame: University of Notre Dame Press, 1989), p. 134.
6. The point is made emphatically by the story of Nebuchadnezzar in Daniel 4:25–34.
7. See, for example, John S. Grabowski, 'Person: Substance and Relation', *Communio* 22 (Spring 1995): pp. 139–44.

8. See Grabowski, 144–63; and Kenneth L. Schmitz, 'The Geography of the Human Person', *Communio* 13 (Spring, 1986): 27–48.
9. Gilbert Meilaender, 'Begetting and Cloning.' Address to the National Bioethics Advisory Commission, March 13, 1997. Reprinted in *First Things* (June/July, 1997), p. 42.
10. Meilaender, p. 42.
11. Cf. Germain Grisez and Russell Shaw, 'Dolly redux: Should we clone human embryos?', *Our Sunday Visitor* (June 22, 1997), p. 17.
12. Cf. Meilaender, p. 42.
13. See the Congregation for the Doctrine of the Faith, *Donum vitae*, II, pp. 4–5.
14. On the primacy of instrumental reason see Charles Taylor, *The Ethics of Authenticity* (Cambridge, MA: Harvard University Press, 1991), pp. 93–108.
15. Cf. Pope John Paul II, Encyclical Letter, *Evangelium vitae*, nos. 4, pp. 10–24.
16. The phrase is that of Sharon Begley, 'Little Lamb Who Made Thee?' *Newsweek* (March 10, 1997), p. 54.

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Ethics & Medicine (1998) **14:3**, 72–77 0226–688X

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Cochlear Implants in Children: Ethical Considerations from the Perspective of a Christian Parent

Keywords: deafness, sign language, hearing aid, oralism, manualism, American Sign Language, meaningful communication, children, Signing Exact English.

Parents face decisions every day which impact the well-being of their children. As parents, my wife and I have found that we are not immune to having to make decisions in the best interests of our children. We have two children, one boy and one girl. Our daughter, Jocelyn, is four years old, and she is deaf.[1]

Without hearing aids, Jocelyn cannot hear sound unless it is of such volume that it begins to provide tactile stimulation as well, approximately 90 decibels (dB) or more. With hearing aids, she is still showing no perception of sound in her left ear, while she can detect sounds as low as 35 dB at some frequencies in her right ear. Thirty-five decibels is well within the range of spoken sound. Conversely, she is not able to detect sound at that volume at all frequencies and, therefore, is able to detect only portions of spoken sound. As a result, she requires therapy to decipher the sounds she can detect, and even more extensive therapy to begin to articulate the sounds that are required to speak clearly enough to be understood.

We were presented with the fact that Jocelyn was deaf when she was eighteen months of age. We had been discussing, during the testing process, how we would respond to a diagnosis of deafness. We had decided to use sign language as a primary mode of communication because we had little or no knowledge of any other course of action to address deafness.

On the day that the Otolaryngologist told us of her deafness, he also explained that there is a device called a cochlear implant which could assist her, but that the technology is still being developed and that by the time Jocelyn is of age to make her own decision, the technology may be so advanced that it could nearly duplicate sound. We were unaware of the cochlear implant, and had already determined to approach her deafness with manual language.

Over the past several years we have met many professionals who work with deaf children, parents of deaf children, and Deaf persons from the community. During that time we have come to discover that the use of the cochlear implant as an assistive device for deaf children is an extremely controversial option. The Deaf community is the greatest opponent of the device, and abhor any discussion of the option. Professionals who have accepted the oral philosophy of educating deaf children praise the implant. These two extremes are the bookends of a vast spectrum of options in between.

To implant or not to implant, that is the question. This article will discuss many factors involved in parents' decision to use this form of technology with their child. Specifically, I will address the ethics of parental decision making that will effect their child for the rest of her life. There are aspects of this decision that will have lifelong ramifications for the child in her physical, social, emotional, psychological, educational, and spiritual development.

I must admit bias on this issue. While there is no truly objective person on the earth, I will do my best to maintain

as much objectivity as possible while I discuss these issues, and look at the pros and cons of each argument.

Preliminary Points of Clarification

To discuss appropriately whether or not it is right to implant a child, there are some issues that must be clarified and some terms must be defined.

What is deafness?

Deafness is an often misunderstood term. It is frequently used to describe a person who is unable to hear. The most significant level of deafness is profound deafness. Levels range from profound, severe, moderate, and mild, to a term which is most common, 'hard of hearing'. In general, those who are hard of hearing to moderately deaf, are referred to as 'hard of hearing'. Those who are severely to profoundly deaf are considered 'deaf.' For the purposes of this article the term 'deaf' will be used most frequently because a person must be deaf to be a candidate for a cochlear implant.

There are two forms of deafness: conductive and neurological. Conductive deafness is the less common form which occurs when one of the physical structures of the outer or middle ear is either malformed or missing. As a result, there is limited sound transmission to the cochlea. The cochlea is the apparatus of the inner ear containing the nerve endings which sends a signal to the brain to process for comprehension.

The more common form of deafness is neurological, or 'nerve deafness'. Nerve deafness occurs when there is some impairment of the cochlea itself. The cochlea is an organ in the inner ear that is the shape of a snail shell. Inside the 'shell' is fluid, and the nerve endings line walls of the shell, as tiny hairs. When sound is conducted through the outer and middle ear, the fluid inside the cochlea is disrupted and causes the hairs to be moved which then sends a neurological message via an electrical and chemical process to stimulate the appropriate centre of the brain, and thus we 'hear'. Hearing aids are used for either conductive or nerve deafness. The cochlear implant is used only to assist people who experience nerve deafness.

What is a basic hearing aid?

When one refers to a hearing aid, one is usually indicating the small electronic device that is placed either in the ear canal or behind the ear with a tube leading into the ear canal, that simply amplifies and defines the sound that is stimulating the ear drum. It is the most common form of device used to assist a person with hearing loss.

What is a cochlear implant?

A cochlear implant is a device that is used to assist in the perception of sound. It involves the surgical insertion of a somewhat flexible needle-like electrode into the cochlea. The most common and effective form of electrode has twenty-two bands (or channels) that will discharge an electrical pulse into the cochlea, stimulate the auditory nerve to send a signal to the auditory centres of the brain, and thus provide a simulation of sound perception. The electrode is attached to a wire which is attached to a magnetic device that is placed in a hole that has been drilled into the skull just behind the outer ear. This magnetic device serves as a connector to another wire that is attached to a microphone that lies over the back of the ear just as with a standard hearing aid. There is another wire leaving the microphone that goes to a processor about the size of a small 'walkman' type radio.

Sound enters the microphone, sending a signal to the processor, which changes the sound into an electronic 'message' that is sent to the electrode in the cochlea where one or more of the twenty-two channels fires an electrical stimulation at the proper intervals to simulate what the missing or malfunctioning structures would send to the auditory nerve.

Two Philosophies

There are two philosophical approaches to deafness among children. One approach basically states that we live in a hearing world where it is advantageous to be able to communicate orally with one another, and is therefore called the 'oralist' approach. The other approach maintains that a person who is deaf, can fully and effectively communicate using manual language, with an underlying goal of teaching speech-reading and speech skills for communicating with the hearing. This is the 'manualist' approach. Manualists work and function in the hearing culture but primarily socialize with persons of the Deaf subculture. There are many stigmata attached to each of these philosophies, and there is great debate as to which is the 'better' philosophy.

Oralism

A pure oralist would never allow manual language or gesturing to be used, believing that is an unclear and unsophisticated form of communication, hindering the acquisition of speech. As a result, when one approaches a deaf or hard of hearing person, the oralist expects the person to rely upon whatever hearing does exist with or without assistive hearing devices, as well as lip reading or speech reading to comprehend the message being spoken. This approach is quite successful with persons who are hard of hearing and whose assistive devices can bring sound within the range of the normal spoken word. Educationally then, a person who is able to speak and listen orally is able to learn the phonetic method of understanding written English and 'sound out' words to read and write.

As the severity of hearing loss increases, the likelihood of success typically declines, although there are 'success stories' such as Heather Whitestone's, Miss America 1995. The oralist would thus support the use of the cochlear implant for the deaf as it is one more tool to assist in the detection and comprehension of the spoken word. The oralist views deafness as a deficiency. It is a disability, an

infirmity, or even an abnormality. As a result, the oralist looks for a cure, or the closest correction of the problem as possible. They might adopt assistive devices such as hearing aids, or prosthetic devices such as the cochlear implant. The goal is to habilitate or rehabilitate the deaf to a point where he or she may function 'normally' in society.

Manualism

Those who use the manual approach to educating the deaf have less concern for the comprehension and development of speech and hearing, but are more concerned with the acquisition of language, typically American Sign Language (ASL). American Sign Language, a complete language, has its own manual vocabulary and syntactical structures. Those who support the ASL approach to teaching view oralism as an attempt to force a person in one cultural minority to acclimate to a non-native culture.

Manual language can be understood by any child who can see, and thus communication can occur from birth just as with a hearing child. The only difference is which language is being used.[2] In more progressive programmes, American Sign Language is used to communicate interpersonally, and English is taught as a second language for the purposes of reading and writing. Another widely used method is Signed Exact English (SEE). This method uses manual signs to represent English words, and these signs are placed in English word order. Both of these approaches are being researched to determine effectiveness in meeting educational standards.

The 'Deaf' manualist prefers to view the deaf as people who are different, but not abnormal. Deafness is not a condition, malady, or infirmity; rather it is a uniqueness to be celebrated just as is any uniqueness in a pluralistic society. There is, therefore, no need for assistive devices and prosthetics to normalize the deaf. Instead, alternative methods are utilized to assist the deaf in enjoying 'success'. As a result, the deaf maintain their own language, their own schools, their own culture, norms, and ethics. They would compare themselves to racial and ethnic groups who maintain the ideals of their 'society' or 'sub-culture'. Some may even go to the extreme of desiring to remove deaf children from hearing parents because of cultural differences between the hearing and the deaf.

The Major Arguments

Should parents choose a cochlear implant for their deaf child? There are several issues worth addressing with respect to arguments favouring or opposing cochlear implantation of deaf children. These will be categorized as surgical, psycho-social, educational, economic, and parental issues. These categories are all closely interrelated.

Surgical Issues

Proponents of cochlear implantation report that surgery is not a significant issue. The patient undergoes general anesthesia for a procedure that is able to be completed by any skilled surgeon. The operation is completed often on an outpatient (23 hour) admission. There are seldom complications, and recovery is easy because there are no major muscle groups involved. Opponents of cochlear implants complain that the procedure is still considered elective and experimental.[3]

Next, the outcomes of anaesthetization are not perfectly consistent. Each patient is unique and children as young as two years old (and possibly younger) may have no history of allergic reaction to anesthesia. Also, with a child as young as three to five years of age, non-emergency procedures are often questionable because it is difficult to apply the proper dosage of anesthesia to patients with very low weights. In brief, anesthesia poses the greatest risk of the surgical procedure itself.

Other surgical considerations are the possible risks and complications of the procedure itself. The insertion of the electrode into the cochlea causes the destruction of the nerve endings. Additionally, 'Major complications (i.e., those requiring revision surgery) include flap problems, device migration or extrusion, and device failure. Facial palsy, although considered a major complication, is distinctly uncommon and rarely permanent'.[4] Device failure, while rare, is an additional major complication. 'Reimplantation is necessary in nearly 5 percent of cases because of improper electrode insertion or migration, device failure, serious flap complication or loss of manufacturer support'.[5] 'Minor complications, that is, those that resolve without surgical intervention include unwanted facial nerve stimulation . . . [and] in percutaneous devices, pedestal infections'.[6] These conditions are considered to be easily rectified. Long-term complications include flap breakdown, electrode migration, receiver-stimulator migration, and otitis media. An additional medical concern is the fact that in the case of Magnetic Resonance Imaging, the implant includes a magnetic 'pick-up' which interferes with MRI technology. As a result, this diagnostic medical technology is unavailable to implant patients. Some patients also complain of sensitivity to static electricity, muscle spasms, and headaches.

Finally, the procedure is also a lifetime decision. The patient will keep the device for life. There is concern that if the device were removed, there might be irreparable damage to the physical structure of the inner ear resulting in further hearing loss.

Psycho-social Issues

A typical early intervention process may occur in the following way: When an Ears, Nose, and Throat (ENT) specialist informs parents that their child is deaf, the parents are faced with life-changing news. Every parent, unless there is prenatal diagnosis, is led to believe that their child will have all of the faculties of every other child. They will be able to see, hear, talk, walk, etc. At the point that they are informed of their child's deafness, most parents will experience denial, anger, bargaining, depression, and hopefully, acceptance. Long before acceptance, there are a number of professionals who enter the life of the family—such as audiologists, speech and language specialists, educators,

physicians, and depending on the etiology of the deafness, geneticists and surgeons.

In all of this turmoil parents are typically led by the professionals to move toward a philosophical approach to deafness. These philosophies are described above, and are usually biased toward the educational and experiential background of the professionals. As a result, parents often choose the philosophy espoused by the professional team performing the initial testing. If the programme is orally focused, the parents will have tendencies toward the oral approach. If the programme is manually focused, the parents will have manual tendencies.

As stated above, the oralist will focus on the need to address speech and hearing, whereas the manualist will focus on learning a full language. In a conversation with a major representative of a local chapter of a national orally-focused organization, the representative continually stressed the need for language when discussing the option of manual language. She consistently avoided admitting that American Sign Language is a legitimate language, and focused on spoken English an the only viable language option. As a result, she raised her deaf child with the oral philosophy, and her daughter, therefore, never communicated until age five. The movie *Mr. Holland's Opus* illustrated creatively, and for the most part accurately, the frustrations experienced by a child who is unable to communicate with his parents.

In contrast, deaf children who use manual language such as ASL are able to communicate with parents at the same developmental ages as hearing children, and there have been reports of children who use manual language even earlier than their hearing peers use spoken language.[7] These children will then have less frustration because they develop the ability to communicate their wants and desires more effectively and at an earlier age than their peers whose parents use oral methods.

The oralist will encourage the parents to improve their child's hearing with any method medically possible. In their grief, parents may listen to such promises and choose to begin the process of implantation without adequately exploring other options. Companies that produce the implant will be pleased to represent their product. They will cite statistics which show that people who use the implant have better comprehension of words after the implant than before, and may even show a video of people using the telephone, a task which is nearly impossible for most deaf people. The manufacturer will claim that the surgical procedure is both safe and effective, and will present research papers as well as personal testimonies to support their position. Unfortunately, these methods are suffused with marketing techniques which tend to play on the emotions of parents who are already grieving over their child's recently diagnosed deafness.

I personally attended a 'sales' session of this sort. There was no intentional deception in the presentation. It was an honest attempt to show that the cochlear implant is a viable alternative as an assistive device for children who are deaf. The session began with the video that glorified the positive results of the implant. Then another video illustrated the speech skills and speech detection skills with implants. An actual implant was displayed for the attendees. An adult implantee also came to the meeting and answered questions regarding his experience with the device. Finally, a manufacturer's representative and a surgeon who had performed numerous implant surgeries were available for questioning.

The initial video is probably the same video described by Marylyn Howe in her article 'Untruths in Advertising.'[8] Howe describes the portrayal of implantees using the telephone and testimonies of adults who had been struggling and now are freed from their deafness through implantation. She argues that these testimonies are devalued by the fact that the implant, firstly, can only take a deaf person and make them hard of hearing, and secondly, that the people in the video had speech before they were implanted, and therefore were likely to be more successful implantees. It has been demonstrated that people who had acquired spoken language before losing their hearing are much more successful candidates of implants, whereas, those who are prelingually deaf are much less successful.[9] This fact is not clearly illustrated in the video. The entire presentation leads to a favourable view of implants.

Unfortunately, one must do research on his or her own to discover the negative factors of implantation. As a result, parents who are already in an emotionally charged situation—either still grieving or seeking assistance because their child's language is not progressing as they had hoped—are now offered quite optimistic information and leave with a promising perspective on implants.

The latter video also had the potential to be misleading. It was illustrative of the importance of additional intensive speech therapy and parental involvement in the ongoing speech development of the child as well as other factors involved in the successes and failures of the implant. The fact that children will require extensive therapy did not appear to be well illustrated.

The first child in the video was a successful implantee. He was shown seated in a chair and a speech therapist was vocalizing a list of words while standing behind him. The boy repeated the therapist's words. The therapist then had a brief impromptu conversation with the boy and he responded quite well, demonstrating that he could hear what she was saying. His speech was easily understood, although it was not speech characteristic of the average hearing child. His was obviously a success story.

Not clearly demonstrated was the fact that the boy's parents were exceptional in their commitment to assisting their son. They had worked closely with him at home, and he was obviously of above average intellect. The boy had had the implant for over two years without significant complications. (One should note that the video taping occurred in a closed environment with minimal background noise. This point is relevant because it has been shown that assistive devices are less effective when used against background noise.)

The next child shown in the video had only had his implant for about a year. He was much less responsive than the first. His skills were very different. He showed little comprehension of the speech therapist's utterances, only repeating a few of her words, and never getting to the point of conversation. Again, the details of the child's psychosocial situation were not given. This child came from a family which was less involved in his therapy due to geographic and economic constraints. His parents allowed sign

language, but made little effort to learn or use it themselves. It is probable that they were just as lax about speech therapy in the home setting. This child was probably an example of the more typical implantee. The third child in the video was not shown because on the day of the taping the batteries were dead in her processor.

Here were three children; one a success story, and two whose stories are yet to develop. Each had surgery with some irreversible results. The success of these examples appeared to be more dependent on the parents than the implants themselves.

Those who research and develop the implants cite repeated favourable reports of success. One article, for example, asserted that '11 of 13 children were able to identify words with consonant cues'.[10] The article also reported that some of the children lacked language skills to understand the prompts of the research team and therefore were unable to participate in the study until later if at all.[11] One would also need to ask if these perception skills were performed in an environment with or without background noise. Presumedly, background noise was controlled, as it would be very difficult to develop such a study in a non-clinical setting such as a working class room. Other studies cite similar positive results, but require further analysis to account for potential biases. Often the 'implant teams' are located in facilities which vie for grants from the manufacturers and researchers, and are thus more motivated to support the success of the programs.

Another psycho-social factor in implantation is how the child will function in society. The hearing culture will likely be a place for the success stories such as the one illustrated above. He will learn to function in the hearing society with only minimal limitations if he continues to progress as he has thus far. But, if he were to decide to be more involved in the deaf community, he would probably be rejected as the Deaf community has a strong aversion to cochlear implants.

This aversion is a protest against the attempt to treat deafness as a physical ailment or malady. Often deafness is viewed as a syndrome in need of extinction. My wife and I were advised to seek genetic counselling after the birth of our daughter in light of the 'risk' of conceiving a second deaf child. This advice has connections to our eugenic past, as when Alexander Graham Bell suggested sterilization of the deaf along with 'other diseased and degenerate persons', so that they will not continue to propagate genetic deficiencies.[12] Ironically, the statistics show that there are more children born deaf to hearing parents than to deaf parents.[13] The Deaf take great offence at this view and are searching for their own identity, wishing to be legitimated by their ability rather than disability.

In light of this fact, many teens with implants (especially if they are not orally successful or enter a manual school) are thrust into the Deaf Community, having a device implanted by their parents, yet are rejected by their community. They are torn between two worlds and anticipate failure in either direction. They are not able to perform to the standards of the oralist (an oral failure) culture, and are rejected by the deaf as misfits who tried to be something they are not. Identity crisis is likely to follow such a scenario.

Educational Issues

The educational philosophies have been illustrated throughout this article. The most significant point to reiterate is the fact that the cochlear implant does not make the deaf child hear, rather it makes the deaf child hard of hearing. Because the child is, at best, hard of hearing, a great number of educational supports are required for her as a student both in and out of the classroom. In contrast, a child who starts out as hard of hearing and is given an assistive device such as a hearing aid is usually able to perceive sound nearly equal to hearing peers, and is able to mainstream into whatever school system is preferred. This is not an option for the child with an implant, and this fact needs to be communicated clearly to parents as a factor in considering the cochlear implant for their child. In other words, the cochlear implant does not open up the options for the deaf child to any significant extent. She will still have a specialized educational process that may be quite similar to her peers without implants, or even manual peers.

Economic Issues

According to Harlan Lane, 'There are no hard figures available, but cost estimates [for cochlear implants] run between $30,000 and $50,000 during the first year.'[14] This accounts for the costs of social workers, medical evaluations, actual surgical and medical need, and follow-up therapies. Much of this cost is covered by insurers, but generally the costs indirectly come back to the public. Across the span of a lifetime, there is an additional $7,767 average for American adult implantees.[15] There are no accurate accounts for American children implantees, but in the United Kingdom the estimate is nearly $85,000 in lifetime costs.[16] The utility of the cochlear implant has been studied and found to be cost effective with respect to the increased quality of life of the implantee in comparison to potential earnings.[17]

These studies assume that implantation will be successful. One to five percent of those who are transplanted experience complications such as device failure, flap problems requiring revision, device extrusion or migration, pedestal infection, pedestal fracture, or other flap problems.[18] More than fifty percent of implantees require antibiotics because of infections related to the connectors.

Another economic issue to consider is the insureability of implantation. Most insurance companies do not cover elective surgeries or the cost of simple hearing aids. This leads one to question the reasons insurance companies (including the federal government in the case of Medicare and Social Security Disability) have chosen to finance an elective and experimental procedure with inconsistent outcomes as is the case with cochlear implantation.[19]

Finally, one must consider the teen rejection issue when considering economics. The device is more of a problem than a help if it is rejected by the user due to sociological, psychological, physical discomfort or lack of perceived gain related to the implant.

Parental Issues: The Ethics of Implanting Children

The final and most important issue is how parents come to a decision regarding cochlear implantation of a son or daughter between the ages of two and five years. Children are evaluated by clinicians and physicians to determine therapeutic eligibility alone. Once deemed eligible, the ethical decision has to be made by the parents. Is the cochlear implant the right or wrong decision to make for the child?

The oralist culture would choose to utilize the technology of the cochlear implant because they will afford any opportunity to assist their child with speech and hearing. The Deaf Culture would argue that under no circumstances should a deaf child be implanted. The oralist values spoken language, the Deaf values a language that operates in her culture. What shall a Christian parent do?

In the Old Testament children were viewed as very important to the family and were considered a demonstration of God's love (Ps. 127:3–5). In the New Testament children were given a place of high honour by Jesus (Mark 10:13–16). The Bible makes it clear that we are to care for our children, honouring God as good stewards of the gift he has given us in our children. The gift of children brings with it a stewardship obligation. Christian parents are to act in the best interests of their children.

The Pauline Household Code may well have implications for parental decisions regarding cochlear implantation: 'Fathers, do not exasperate your children; instead, bring them up in the training and instruction of the Lord' (Eph 6:4, NIV). One could easily argue that there is nothing more exasperating than the oral approach for a deaf child. The child can perceive only the faces of parents staring with varied and confusing expressions. Lips move with no audible sound or vocalizable meaning. There is little meaningful communication. The child is in a world where language does not exist. Children raised orally grunt and point in an attempt to communicate, and parents are discouraged from responding to gesturing. They are instructed to respond only to vocal emissions that are related to verbal communication. As a result, in her attempts to communicate with others, she meets with little but frustration. (I would argue that parents who opt for manual methods but do not learn sign language encounter the same predicament.)

Next, Paul teaches parents in Ephesians to 'bring [children] up in the training and instruction of the Lord' (Eph. 6:4). Interestingly, Schools for the Deaf began in France in 1755 with the purpose of reaching the deaf with the Gospel of Jesus Christ and 'save their souls'. This goal continued in America under a seminarian named Gallaudet.

If parents cannot communicate adequately using the oral method, there is no way effectively to train and instruct their children in the things of the Lord. The entire focus of the oralist is on teaching speech recognition and production. This sometimes takes years to achieve, when all the while they could have been using manual language. We chose to teach our daughter to sign so she could communicate at an earlier age and, hopefully, understand her world, including the gospel of God's grace, much earlier.

Conclusion

There are many philosophical and practical reasons why the cochlear implant is not yet an adequate therapy for all deaf children. While for some it has been successful, the successes are more a result of the parents' extraordinary effort than of the utility of the implant itself. Similar results can be attained by utilizing hearing aids and manual language.

Every parent whose child is deaf must make a decision that will impact that child's quality of life for the foreseeable future. Making such decisions is exceedingly difficult. Clearly, however, the child's best interests much be kept in view. We chose to teach our deaf child manual language because we thought it was in her best interest. If we had to face the decision again, I believe we would make the same choice.

Notes

1. Throughout this article I will use the following convention: 'deaf' with a lower case 'd' is the physical condition of being unable to hear. 'Deaf' with a capital 'D' is a title for a specific sub-culture in our pluralistic society. There are political implications of this title which go far beyond the scope of this article.
2. Many people are impressed by Jocelyn's ability to communicate with signing at such a young age. I respond by pointing out that she is really communicating at a normal level for her age. Just because she doesn't use spoken English does not mean she is abnormal, anymore than a person who speaks Chinese is abnormal. The point is that Sign Language is a full language.
3. 'NIH Consensus Statement: Cochlear Implants in Adults and Children', National Institutes of Health, May 15–17, 1995.
4. Harlan Lane, *The Mask of Benevolence: Disabling the Deaf Community* (New York: Alfred A. Knopf, 1992), p. 217.
5. NIH Consensus Statement: Cochlear Implants in Adults and Children.
6. Ibid.
7. Barbara Luetke-Stahlman, forward to Gerilee Gustafson and Esther Sawolkow, *Signing Exact English* (Los Alamitos, CA: Modern Signs Press, 1993), p. v.
8. Marylyn Howe, 'Untruths in Advertising: Cochlear Implants', *Viewpoints on Deafness, A Deaf American Monograph* 42 (1992), pp. 67–68.
9. NIH Consensus Statement, p. 6.
10. Ann Geers and Chris Brenner, 'Speech Perception Results: Audition and Lip-reading Enhancement', *Volta Review* 96 (5), p. 97.
11. Ibid.
12. M. Haller, Eugenics: *Hereditarian Attitudes in American Thought* (New York: Rutgers University Press, 1963), p. 133.
13. Matthew S. Moore and Linda Levitan, *For Hearing People Only* (Rochester, NY: Deaf Life Press, 1993), p. 184.
14. Harlan Lane, *The Mask of Benevolence*, p. 206.
15. Quentin Summerfield, 'Cost-Effectiveness Considerations in Cochlear Implantation', NIH Consensus Development Conference on Cochlear Implants in Adults and Children, May 15–17, 1995, *Program and Abstracts*, p. 76.
16. Ibid.
17. Ibid., pp. 75–79.
18. Derald E. Brackman, 'Percutaneous Connectors in Cochlear Implantation', NIH Consensus Development Conference, p. 98.
19. Mary Jo Osberger, 'Effect of Age at Onset of Deafness on Cochlear Implant Performance', NIH Consensus Development Conference, p. 28.

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Ethics & Medicine (1998) **14:3**, 78–84 0226–688X

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Prenatal Genetic Testing: The Need for Legislation

Keywords: genetic disease, pregnancy termination, prenatal testing, consent, informed choice, duty of care, Bolam test, wrongful life, abortion, handicap, negligence action, Code of Practice

Introduction

A large proportion of human ill health has a genetic basis (Weatherall 1991). In 1966 an important step was made towards eliminating genetic diseases with the development of a technique to analyse the chromosome constitution of a fetus *in utero*. This opened up the possibility of terminating a pregnancy when abnormalities were found to be present. Although first applied to gross chromosomal abnormalities, the methodology was extended to the inherited genetic diseases following the development of recombinant DNA techniques in the 1970s. Prenatal screening programmes have reduced the incidence of β-Thalassemia in Sardinia from 1 in 250 live births to 1 in 1,200 live births, thus preventing more than 90% of cases of the disease (Cao 1990). The techniques have also been applied to Tay-Sachs disease, Cystic Fibrosis and Muscular Dystrophy.

As more and more genes responsible for genetic disease are identified (for example, through the human genome project (British Medical Association 1992) it will become possible to offer prospective parents a whole battery of genetic tests for their offspring. Potentially, parents could be given a profile for the genetic health of their fetus in order to make an informed decision as to whether or not to continue with the pregnancy.

The English law has not kept pace with these changes. No laws have been specifically designed to control prenatal genetic testing but the existing torts of battery and negligence, and statutes, such as the Abortion Act 1967 (as amended in 1990) and the Congenital Disabilities (Civil Liability) Act 1976, all may apply. Their shortcomings in regulating prenatal genetic testing are considered here under the headings of the surgical intervention, the genetic tests, and the abortion.

The Surgical Intervention

In order to carry out prenatal genetic testing, some fetal material must be removed from the pregnant woman, and this generally involves one of two surgical interventions. During amniocentesis, a small quantity of amniotic fluid is withdrawn and the cells are cultured to provide enough material for analysis. The less well-established method of chorionic villus sampling (CVS) involves the removal of chorionic villi in the first trimester of pregnancy (Doran 1990). The results are obtained earlier in the pregnancy than using amniocentesis, which is advantageous if a termination is to be performed. However, the technique is associated with a higher miscarriage rate than amniocentesis (4% increased risk of miscarriage compared to a 1% increase for amniocentesis, although these risks are approximate and depend on the equipment available and the practitioner). There is also growing evidence that performing CVS is associated with an increased risk of limb and facial defects, and possibly brain damage, especially when performed before 9 weeks (Firth 1991; Firth 1994).

There are a number of legal issues pertinent to the actual surgical intervention. They can be divided into issues of consent—what does, and what does not, constitute consent to a clinical procedure?—and issues of the duty of care, in particular with respect to risk disclosure and prenatal injury.

Valid Consent to the Clinical Procedure

The tort of battery protects the right to bodily integrity, that is, the right not to be touched without consent. This was confirmed in *Re T (adult refusal of treatment)* [1992][1] by Lord Donaldson MR who stated that 'an adult patient who [. . .] suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered'. Consent is valid only if it is given by a competent person, if it is informed, and if it is voluntary.

a. *Capacity to consent* It was established in *Gillick v. West Norfolk and Wisbech AHA [1986]*[2] that capacity to consent is centred on understanding, and in RE *T [1992]*, Lord Donaldson MR, stated that 'every adult is presumed to have [. . .] capacity [to consent], but it is a presumption which can be rebutted'. In the case of prenatal genetic testing the presumption needs serious examination because the procedure is so complicated and intrinsically difficult to understand. Thorpe J went some way towards further defining competence by recommending a three-step analysis in *Re C (Refusal of medical treatment) [1994]*[3]: Firstly, could the patient comprehend and retain the necessary information? Secondly, did he believe it? Finally, had he weighed the information, balancing risks and needs, to arrive at a choice?

But what is 'the necessary information' in the case of prenatal genetic testing? It could be defined in a narrow sense, meaning only the information concerning the actual surgical intervention (that is the amniocentesis or CVS), or in a broader sense, namely the information concerning the surgical intervention, the genetic tests which follow, and the possible termination which may be offered as a result of the tests. Since the genetic tests and the possibility of ending the pregnancy are so integral to the purpose of the intervention, it is suggested here that the latter is the correct interpretation. Thus, in order to be considered competent, the pregnant woman must understand not only the nature of the intervention, but also the nature of the genetic tests and the possible termination.

If this is the correct interpretation of the law, then it is questionable whether many of the women undergoing prenatal diagnosis are legally competent. There are many barriers to the woman's ability to 'weigh the information and balance risks and needs to arrive at a choice' (*per* Thorpe J in *Re C*). It is extremely difficult for the pregnant woman to weigh up the risks of the surgical intervention against the risks of bearing a child with a serious handicap. One study shows that the majority of women who agreed to prenatal testing had not seriously considered an abnormal result (Korenromp 1992). Even if she is able to conceive of the risk of a positive result, she will not know the full implications of raising a child with the disability unless she has already had a child with a similar handicap or has had very close contact with such a child.

So what does the English law say about those women who are not considered competent to consent to prenatal genetic testing? It is a matter for some concern that *Re F (A Mental Patient: Sterilisation) [1990]*[4] allows the doctor to act as a quasi-proxy for adults who are not competent to consent to medical treatment. The House of Lords held that beneficial medical treatment might be performed on incompetent adults, and that 'the doctor must [. . .] act in the best interests of his patients, just as if he had received his patient's consent to do so' (*per* Lord Goff). The limits to such intervention are set by the Bolam test,[5] that is, the doctor acts in the best interests of the patient if a responsible body of medical opinion supports his actions.

Could a doctor really carry out a surgical intervention on otherwise mentally capable women who simply did not fully understand the complicated procedures involved in prenatal genetic testing? Clearly this would be inappropriate and unlikely. It would go against Lord Donaldson's statement in *Re T* which accords the right to refuse medical treatment to any adult who 'suffers from no mental incapacity'. Furthermore, Lord Goff stated in *Re F* that the legal justification for this judgement was 'one of necessity'—the underlying reason for the judgement being that mentally incapable people should not be denied beneficial medical treatment. *Re F* was clearly not intended to cover otherwise mentally capable women who are not capable of understanding prenatal genetic testing. However, there is a need to protect such women and this protection is not currently provided by the English law.

b. *Information regarding the nature and purpose of the treatment* A lack of information can lead to an action in battery if there is insufficient information regarding the nature and purpose of the treatment. The scope of the tort of battery was established in *Chatterton v. Gerson* [1981],[6] namely 'once the patient is informed in broad terms of the nature of the procedure which is intended, and gives her consent, that consent is real' so that it affords a defence to battery (*per* Bristow J). Again, we are faced with the question of what, in broad terms, is the nature of the procedure? Since the whole purpose of the surgical intervention is to provide information which may lead to termination of pregnancy, it would seem logical to assume that this purpose is an integral part of the procedure, and that a woman must therefore be informed of the nature and purpose of the surgical intervention, the genetic tests which follow, and the possible subsequent termination.

There is much evidence that the information currently given to women is inadequate, and that a woman's ability to make an informed choice is severely compromised as a result (Forrant 1985). One source states that doctors sometimes say that they can 'prevent' the baby from having a genetic disease, but mean that they can abort an affected fetus (Birke 1990). Professor Marteau has found that 'on about 50% of occasions [screening] tests were presented as routine; since such tests were presented as being for reassurance, rather than as a means of giving the choice of whether to continue with an affected pregnancy, women took them without due consideration' (Marteau 1995). The recent report of the House of Commons Science and Technology Committee (1995) stated: 'If the purpose of any test is to allow parents to consider whether to continue with an affected pregnancy, this should be made clear and the parents should be given the choice of whether or not to take the test.' In a similar vein, the Council of Europe (1990) principle 8, recommended that information must 'cover the purpose of the tests and their nature, as well as any risk which these tests present'. These statements have no legal force, and such clauses should be included in the legislation on prenatal genetic screening.

Whether this inadequate information vitiates consent has not yet been tested before the courts, but since English judges are extremely reluctant to use the tort of battery in medical cases it is unlikely that the courts would accept this argument. An action in negligence is much more likely to succeed and will be discussed shortly.

Another problem concerns the use of techniques which are still in their infancy, such as CVS. Is it obligatory to inform the patient that there are some concerns about the safety of the technique? As the English law stands at present, the legal status of innovative techniques depends on whether the doctor's intention is to acquire knowledge and not merely to care for his/her patient (Kennedy and Grubb 1994). Since most of the CVS being conducted in England are carried out for therapeutic reasons, not for research reasons, a lack of information regarding the risks of the surgical intervention is unlikely to result in a successful battery action under English law.

c. *Was consent given voluntarily?* Unless information is complete and presented impartially, the subject could be at risk of manipulation, either deliberately or subconsciously, by the counsellor. The genetic counsellor's role should be as neutral and objective as possible. It should be clarified to counsellors that their obligations are to the

pregnant woman and not to society in general, or to the fetus.

The possibility of coercion was recognized by the Council of Europe (1990) in its recommendation, principle 4 which states that 'the counselling must be non-directive; the counsellor should under no condition try to impose his or her convictions on the persons being counselled but inform and advise them on pertinent facts and choices'. A similar statement should be included in the English legislation on genetic testing.

The Duty of Care Towards the Patient

As well as obtaining valid consent from the patient, any surgical intervention must be carried out with proper skill and care on the part of all members of the medical profession involved. Inadequate care or lack of competence would constitute negligence. The plaintiff must show that there was a duty of care, that this duty of care was breached, and that the doctor's fault caused the injury.

As regards the surgical intervention necessary for prenatal genetic testing, there are two potential plaintiffs: the pregnant woman and the fetus/potential child. Either would have to establish that the doctor owed him/her a duty of care. There are two likely breaches of duty: a failure to disclose information about the intervention (for example, the increased risk of miscarriage and fetal handicaps in the case of CVS), and a failure to carry out the surgical intervention with due care.

a. *Duty of care towards the pregnant woman* There would generally be no difficulty in establishing that the doctor owed the pregnant woman a duty of care. The question of whether the doctor breached this duty of care is judged using the '*Bolam* test'. In *Bolam v. Friern Hospital Management Committee [1957]*[7] the judge held that a doctor is not negligent if he acts in accordance with a practice accepted at the time as proper by a responsible body of medical opinion, even though other doctors adopt a different practice, which is conveniently referred to as the *Bolam* test.

Information disclosure The *Bolam* test was applied to information disclosure in *Sidaway v. Board of Governors of the Bethlem Royal Hospital [1985]*[8]. The case would appear to establish that a doctor has not breached his/her duty of care if, at that time, a responsible body of medical opinion did not disclose the information either. However, the precedent set by *Sidaway* is ambiguous since only Lord Diplock applied the *Bolam* test unequivocally, and there is increasing support for not relying entirely on the *Bolam* test. For example, in *Bolitho v. City and Hackney HA* (1993),[9] Farquaharson LJ held that 'it is not enough for a defendant to call a number of doctors to say that what he had done or not done was in accord with accepted clinical practice. It is necessary for the judge to consider that evidence and decide whether that clinical practice puts the patient unnecessarily at risk'. Likewise, *Defreitas v. O'Brien and Another [1993]*[10] suggests that the last word on whether a doctor is negligent rests with the court and not with medical experts. These cases provide hope for future change in the approach of the English courts to such medical cases.

Even if the patient proves that the doctor has breached his/her duty to inform, it still has to be shown that the doctor's conduct caused the harm. In the case of risk disclosure, the plaintiff has to prove that she would not have undergone the procedure had she known about the risks. Under English law, this question is analysed subjectively, in other words, the patient has to prove that she would not have undergone the procedure had she known the risks. The burden of proof lies with the plaintiff to convince the court that, given the information, she would not have undergone the tests.

Surgical intervention A woman can also bring a negligence action if she believes that the surgical intervention was not carried out with proper skill and care. Again, she would have to show that the doctor breached his/her duty of care, as judged using the *Bolam* test.

Leaving aside the possibility of a poorly performed surgical intervention, there is still a question-mark over CVS *per se*. The responsible use of CVS before the possible association between the technique and fetal abnormalities came to light is unlikely to lead to a successful negligence action, as a responsible body of medical opinion accepted the practice as proper at the time. However, since the discovery of the possible detrimental effects of CVS, there may be a chance of a successful negligence action despite evidence that other doctors would have behaved in a similar manner. The cases of *Bolitho and Defreitas* discussed above indicate that 'it is not enough for a defendant to call a number of doctors to say that what he had done or not done was in accord with accepted clinical practice. It is necessary for the judge to consider that evidence and decide whether that clinical practices puts the patient unnecessarily at risk' (*per* Farquaharson LJ in *Bolitho*).

If it were established that the doctor did breach his/her duty of care, there is still a need to prove causation, in other words, that the doctor's conduct could and did cause the harm. This will be problematic in the case of CVS, since the evidence linking CVS to fetal abnormalities is patchy. Even if the court accepts that a negligent action can cause a particular injury, the case may fail if the negligent action was only one of the possible causes of the damage (as in *Wilsher v. Essex Area Health Authority* [1988][11]). This reflects a general problem with proving causation, namely that the burden of proof lies with the plaintiff and any uncertainty about causation is likely to result in failure of the action.

b. *Duty of care towards the fetus/potential child* It will generally be clear that the doctor owes a duty of care to the pregnant woman. It could also be argued that (s)he has a duty of care towards the fetus. However, under English law, the fetus itself has no legal status. In a landmark decision in *Paton v. BPAS [1979]*,[12] Sir George Baker, P, stated that 'the fetus cannot, in English law [. . .] have any right of its own at least until it is born and has a separate existence from the mother.' The fetus is afforded a certain measure of protection by the Congenital Disabilities (Civil Liability) Act 1976, but his protection comes into existence only once the child is born alive.

Nevertheless, a child could bring a claim for prenatal injury if s(he) was born with an injury allegedly caused by the negligence of another prior to birth. Section 1(2)(b) of the Congenital Disabilities (Civil Liability) Act 1976 provides that an action can arise from an occurrence which 'affected the mother during her pregnancy, or affected her

or the child in the course of its birth, so that the child is born with disabilities which would not otherwise have been present'.[13] It is questionable whether the damage allegedly caused by CVS would be covered by this section. The words 'affected the mother' are problematic, since the meaning of 'affected' is ambiguous, a point raised for the case of X-ray damage by Kennedy and Grubb (1994). If 'affected' means 'has a detrimental consequence upon', then although CVS may affect the mother in this sense (for example by causing her pain or discomfort), there is no causal connection between this effect and the prenatal injury. If on the other hand, 'affect' means merely 'to act upon' or 'to influence', then CVS affects the mother (since CVS is an invasive procedure), and there is an alleged causal connection between the mother being 'affected' in this sense and the disability of the child.

Section 1(3) further defines the type of prenatal occurrence which is actionable under the Act. The defendant is 'answerable to the child if he was liable in tort to the parent or would, if sued in due time, have been so'. The plaintiff would have to cross the hurdles discussed in the previous section for the pregnant woman, and again the claim would be most likely to founder for lack of proof of the cause of the disability.

As well as the risk of development abnormalities induced by CVS, both amniocentesis and CVS are associated with an increased risk of miscarriage. Since the law protects the fetus from prenatal injury, it may be expected that there would be some protection against prenatal death. However, the legal protection against prenatal injury comes into existence only if the child is born alive and therefore does not apply in the case of miscarriage. This creates the anomalous situation recognized by one US judge; 'to deny a stillborn recovery for fatal injuries during gestation while allowing such recovery for a child born alive would be to make it more profitable for the defendant to kill the plaintiff rather than scratch him'.[14] It could be argued that such actions are unnecessary, since the mother can bring a straightforward claim for personal injuries, as was the position in *Bagley v. North Herts HA [1986]*[15] (Whitfield 1993). Thus although there is no civil action available to the fetus for its negligent death, the law does provide compensation for those whose ambitions to be parents are wrongfully frustrated due to others' negligence.

The Genetic Tests

Once the fetal material has been obtained, there are two broad approaches to the identification of genetic diseases. When the gene responsible for the disease is known, direct methods can be used to detect specific mutations in that gene. On the other hand if the gene responsible for genetic disease is not known, markers can be identified which co-segregate with the disease (Bell 1990). The direct methods are obviously favourable, but even here, effective prenatal diagnosis depends on there being only a limited number of mutations within a given population group. Moreover, new or unusual mutations will not be detected and therefore a negative result will not necessarily mean that the child will be born free of the defect.

The indirect methods are associated with more pitfalls because the procedure depends on the detection of a region linked to the genetic defect rather than the genetic defect itself. These methods are only feasible if there is tight linkage between the gene defect and the marker region, and even then, genetic recombinations can separate the linked polymorphism from the defect itself, producing an inaccurate result (Bell 1990). Thus, even for single gene disorders, which are the simplest to diagnose, there are problems with accuracy. The situation is even more complicated for diseases with a multi-factorial nature such as hypertension, breast cancer and asthma.

For any genetic screening programme, prediction of disease is imperfect. Incorrect results will increasingly expose doctors to claims that the genetic tests were negligently performed. One possibility is a false positive result, which if followed by the termination of a healthy fetus, could give rise to a claim for personal injuries by the mother. A much more likely scenario is one where a child is born with a genetic disorder as the result of a false negative test.[16] Failure to detect a genetic abnormality could give rise to an action by the child ('wrongful life') or by the parent ('wrongful birth').

Wrongful life

In some countries, a child born as a result of negligent conduct prior to birth can bring a 'wrongful life' action (Kennedy and Grubb 1994), but such a claim was ruled out by the English courts in *McKay v. Essex AHA [1982]*.[17] Although the judges accepted that the doctor had a duty of care to the mother which included informing her of the advisability of an abortion, they rejected the claim that the child herself was owed a duty of care, since this duty would entail a duty to take her life, which would be contrary to public policy. The judges considered that such an approach would place an 'almost intolerable burden on medical advisers' who might be under 'subconscious pressures' to advise abortions in doubtful cases. In addition to this moral problem, the court faced a practical problem, namely the assessment of the child's damages. Any compensation would have to be based on a comparison between the value of non-existence and the value of existence in a disabled state, the problem being that non-existence is not logically attributable to a subject. Although the issue could have been resolved by compensating for the difference between a healthy life and a defective life, there is also a strong argument that any compensation should come from the state, just as it should ideally provide support for other categories of disabled persons. Why should the child born as a consequence of negligence receive more than another equally disabled child? Harris (Harris 1993) points out that the 'needy should be compensated as of right rather than only if they have the resolution, patience, and resources to go to the law'. Ideally, any negligent act should be appropriately disciplined and the harm compensated within a framework set up by new legislation governing genetic testing.

Wrongful birth

A 'wrongful birth' refers to a claim brought by the parents of a disabled child, born as a consequence of negligence

before its birth (Kennedy and Grubb 1994). The action arises out of the same circumstances as the 'wrongful life' claim, but the problems mentioned above for a wrongful life claim do not arise.

There are no English cases which directly analyse the basis for a wrongful birth claim, but a model for analysis which the English courts might well adopt is provided by the Washington Supreme Court in *Harbeson v. Parke-Davis (1983)*.[18] As with any negligence action, one issue which must be addressed is the extent of the duty of care. The decision in *Harbeson* was that parents have a right to prevent the birth of a defective child and that health care providers have a duty correlative to that right, which requires health care providers to impart to their patients material information as to the likelihood of their children being born defective. The second issue is whether this duty was breached, and this would be measured by the *Bolam* test in the English courts.[19] The third issue is whether damage was incurred. *Harbeson* recognized the birth of a defective child as an actionable injury, although there was some debate about whether the injury was only mental anguish or additionally, the difference between the costs incurred in raising, educating and supervising a handicapped child when compared to a normal child. In this particular case, they decided in favour of the latter, and the outcome of such a decision obviously affected the amount of damages awarded. Finally, there is a need to prove causation, that is, that the negligent action caused the injury.

Thus, although it has not arisen in the English courts, an action for wrongful birth fits within the conceptual framework of the normal law of negligence. The Congenital Disabilities (Civil Liability) Act 1976 may also apply. Section 1(2)(a) provides that an occurrence to which this section applies is one which 'affected either parent of the child in his or her ability to have a normal healthy child'. In the case of a negligently performed genetic test, it could be argued that the doctor's negligence did affect the mother's ability to have a normal healthy child, in the sense that having a disabled child affected her opportunity to have a normal healthy child.

Standards of Screening—When Does the Doctor Breach his/her Duty?

Wrongful life and wrongful birth actions both depend on the ability to prove that a disabled child was born as a consequence of negligence before its birth. The most likely sticking point for such an action will be to prove that the duty of care was breached, which is judged using the *Bolam* test. In the normal course of events, a false negative result would not be considered to reflect negligence, since the genetic tests themselves are by their nature often rather inaccurate. However, it is important to ensure that the standards of screening do not fall below a generally acceptable level. According to the legal rules at present, the standards of screening could be inadequate without incurring liability as long as a responsible body of medical opinion adopted the same practice (although *Bolitho and Defreitas* open up the possibility of another interpretation of the law).

Although there are currently guidelines (Royal College of Physicians 1989; Royal College of Physicians 1991), there is a great need for legislation. This concern was also raised in the recent report by the House of Commons Science and Technology Committee (1995), which recommends that the standards of laboratories offering screening needs to be regulated (para. 104).

The Abortion

The current statutory provisions creating the criminal offences relating to abortion are the Offences Against the Person Act 1861 and the Infant Life (Preservation) Act 1929. The Abortion Act 1967 provided a defence to the crimes under s.58 and s.59 of the Offences Against the Person Act 1861 but did not affect liability for the crime of child destruction under the Infant Life Preservation) Act 1929. The Act was amended by the Human Fertilisation and Embryology Act 1990, and this significantly liberalised the law.

Firstly it included a clause stating that 'no offence under the Infant Life (Preservation) Act 1929 shall be committed by a registered medical practitioner who terminates a pregnancy in accordance with the provisions of this Act'. The Infant Life (Preservation) Act 1929 pertained to the crime of child destruction, that is, abortions on a fetus 'capable of being born alive' (generally considered to be at a gestational age of 28 weeks).

Secondly it altered the grounds providing a defence to abortion in s.1(1). Of particular relevance here is s.1(1)(d), which allows abortions beyond 24 weeks of gestation if there is 'substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'. There are two phrases that require further definition: What constitutes a 'substantial risk'?; and what constitutes a 'serious handicap'?

In any screening programme, prediction of disease is imperfect, and often patients and doctors must interpret complex statistical information. There is no guidance in the law as to what level of probability constitutes a serious risk. Moreover, how serious a risk is clearly depends on what is at stake. Although it would be difficult to lay down specific guidelines, some level of consensus is desirable.

The question of what constitutes a 'serious handicap' was considered by the House of Lords Select Committee before the passage of the 1990 amendment. It was argued that if an unborn child were diagnosed as 'grossly abnormal and unable to lead any meaningful life, there is [. . .] no logic in requiring the mother to carry her unborn child to full term' (Morgan 1991). This would have been consistent with the law on selective non-treatment of handicapped neonates: In *Re J*[20] Taylor LJ stated: 'I am of the view that there must be extreme cases in which the court is entitled to say: "the life which this treatment would prolong would be so cruel as to be intolerable". If, for example, a child was so damaged as to have negligible use of its faculties and the only way of preserving its life was by the continuous administration of extremely painful treatment such that the child either would be in continuous agony or would have to be so sedated continuously as to have no conscious life at all, I cannot think counsel's absolute test should apply to require the treatment to be given.'[21]

However, no such stringent conditions were included in the 1990 Act. A number of amendments to delineate more

clearly the fetal handicap ground were proposed at both the House of Commons and the House of Lords stages, but to no avail (Morgan 1991). Finnis and Keown point out that the amendment actually sanctions abortion up to term on such grounds as cleft palate or hare lip (Morgan 1991). It is also unclear whether the handicap needs to be present at birth or whether predispositions to disease and late onset diseases would also qualify, whether carrier status alone would be considered sufficiently grave, or even whether gender could be considered a handicap if a child is born into a culture where that particular gender is undervalued.

The difficulty of defining whether a handicap is serious, or whether in fact there is a disease at all, has been given more attention in the ethical and legal debates on gene therapy. The Parliamentary Assembly of the Council of Europe drew up a list a serious diseases which may properly be treated by gene therapy (Munson 1992). A similar list of diseases could be constructed for prenatal genetic screening, although it is just as difficult to imagine how such a list can be constructed. Some diseases are clearly serious in all cases, but many diseases have different degrees of severity. Obesity and shortness of stature can be serious diseases, but in their less severe forms concerns about them can be considered cosmetic.

It is interesting that the debate on the limits of gene therapy is generally couched in terms of the rights of the potential person, not in terms of the rights of the mother to decide what sort of child she wants to have. Many feel that clause 1 (1)(d) would be clearer if it were accepted as having been drafted to protect fetal, rather than maternal interest (Mason 1994). The right of the handicapped fetus to abortion could then be comparable to the right of the incompetent patient to forego life-sustaining treatment, a decision made by proxy, based on the patient's best interests (as in *Re J* and in *Airedale NHS Trust v. Bland* [1993].[22]

This interpretation of s.1(1)(d) might appear to undermine maternal rights, and certainly the right of the mother to retain her defective fetus would need careful protection. However, it has the advantage that it would prevent parents and doctors from abusing prenatal diagnosis by aborting for trivial reasons, a possibility which was recognized by the Council of Europe (1990). Principle 2 of their recommendation states: 'tests undertaken for the purpose of identifying a risk to the health of an unborn child should be aimed only at detecting a serious risk to the health of the child'. Likewise, the Nuffield Council for Bioethics *Report on Genetic Screening* (1993) states that the primary requirement of screening is that the target disease should be serious. It does not define what serious is but does delineate what should not be included in genetic screening, namely a characteristic with a genetic component which can not be classed as disease. Distinguishing between serious disease and other conditions would be a task that would fall naturally to a central coordinating body.

Conclusions and Future Directions

The current English law cannot deal adequately with the complicated issues arising from prenatal genetic testing. There are shortfalls in the present legislation on consent to the surgical intervention, for example, there is a lack of clarity concerning the breadth of information that a patient should be expected to internalise. Although a lack of information regarding the risks of the surgical intervention is unlikely to result in a successful battery action under English law, there may be a successful action in negligence. However, the odds are stacked too heavily in favour of the doctor in such proceedings. Various bioethics committees set up by the government and the medical establishment have now drawn up guidelines to govern prenatal testing and most stress that information must be backed up with genetic counselling. The Working Party of the Nuffield Council on Bioethics (1993) recommended that screening programmes should take account of the importance of providing appropriate information for the participant, obtaining consent, and providing counselling, but there is a need for legislation to ensure that standards of information disclosure are maintained throughout the country. This should make the disclosure of information about the nature of the intervention, including risks and the purpose of the procedure, mandatory for genetic testing.

New legislation could be along the same lines as the Human Fertilisation and Embryology Act 1990, which supplements the common law on consent. The 1990 Act contains two requirements before consent can be given, namely an opportunity for counselling and the provision of relevant information. The level of detail required to be disclosed is specified in great detail under the Code of Practice (July 1993), and goes far beyond that which the common law would otherwise require. Although the Code of Practice[23] states that 'a failure on the part of any person to observe any provision of the code shall not itself render the person liable to any proceedings', it has been argued (Kennedy and Grubb 1994) that the code establishes what a reasonable doctor should do, such that failure to comply with the code would constitute a breach of duty. A similar Code of Practice issued by a statutory body could ensure that standards of information disclosure by the medical profession are maintained for genetic testing.

A negligence action is also likely to fail for lack of proof of the cause of disability. In drafting new legislation, serious consideration should be given to the possibility of reversing the burden of proof in such actions. In addition, national guidelines to avoid unnecessary prenatal injury could be given statutory status. An example would be the change in the timing of CVS given the evidence that performing CVS during the early stages of pregnancy is associated with fetal handicap. The standards of laboratories offering screening also need to be regulated (House of Commons Science and Technology Committee 1995, para. 104).

Current legal rules also struggle with the claims of wrongful life, which can arise from negligently performed prenatal genetic tests. A framework of compensation for such cases could be set up within new legislation governing genetic testing.

Finally the law on abortion on grounds of fetal handicap needs clarification. What is a substantial risk? What is a serious handicap? Must the handicap be present at birth or does a predisposition to handicap satisfy the requirement? This legal point is related to the fundamental moral issue of how far one should go in eliminating disease. The House of Commons Science and Technology Committee (1995) in

para. 144 recommends that screening programmes need to be approved before they are introduced, and para. 90 states that there may be a need to consider whether prenatal testing should be offered for particular disorders. National guidelines will be difficult to establish, but are surely preferable to *ad hoc* decisions made on a local or regional level.

A number of professional bodies have also issued such guidelines (Royal College of Physicians, 1989; Royal College of Physicians, 1991), but the UK has no provision to ensure that these are adhered to. Current practice suggests that neither providers nor purchasers are setting or adhering to these standards (Marteau 1995). It is time that the UK government operated by legislation, a point which has been recognised by a number of advisory bodies with an interest in genetic screening, such as the Nuffield Council on Bioethics (1993) and the House of Commons Science and Technology Committee (1995). Both recommend that the government should establish a central coordinating body, the latter suggesting it be called the Human Genetics Commission (1995), which should have power to regulate medical uses of genetics.

Notes

1. 4 All ER 649 (1992) 9 BMLR 46.
2. AC 112 [1985] 3 All ER 402 (1985) 2 BMLR 11 (HL).
3. 1 FLR 31.
4. 2 AC 1.
5. *Bolam v. Friern Hospital Management Committee* [1957] 1 WLR 582.
6. QB 832.
7. 1 WLR 582.
8. AC 871, [1985] 1 All ER 643.
9. 13 BMLR 111 (CA).
10. 4 Med LR 281.
11. 1 All ER 871 [1988] AC 1074 (HL).
12. QB 276, [1978] 2 All ER 987.
13. English legislation excludes claims by the child against its mother except when the injuries are sustained during traffic accidents.
14. *Amadio v. Levin* 501 A 2d 1085 (Pa, 1985).
15. NLJ Rep 1014.
16. This is more likely partly because of the nature of the genetic tests, but also because a false positive will not be detected unless the abortus is analysed for genetic defects.
17. QB 1166, [1982] 2 All ER 771 (CA).
18. 656 P 2d 483 (Wash Sup Ct).
19. The *Bolam* test was applied to negligent diagnosis in *Maynard v. West Midlands RHA* [1984] 1 WLR 634, 639 (HL).
20. (A minor)(wardship: Medical Treatment) [1990] 3 All ER 930 [1991] Fam 33.
21. Although Lords Goff and Browne Wilkinson in *Airedale NHS Trust v. Bland [1993]* 1 All ER 821, (1993) 12BMLR 64 (HL) reserved their positions on this case, preferring to limit the withdrawal of treatment to cases of persistent vegetative state only.
22. 1 All ER 821, (1993) 12BMLR 64 (HL).
23. S.25(6).

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Ethics & Medicine (1998) **14:3**, 84–89 0226–688X

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Eugenic Tendencies in Modern Genetics

Keywords: Human Genome Project, eugenics, science, knowledge, genetic counselling, sexism, medical pressure, reproductive technology, IVF, disability

Introduction

In discussions about the ethical and social consequences of the Human Genome Project, and human genetics in general, there is much confusion about eugenics. The association of the subject with full-scale genocide seems to produce an inability to think clearly on both sides of the debate: it is true that the word is sometimes used as a blunt instrument to silence those who argue for the benefits of current genetics research. On the other hand, there is a converse tendency to avoid discussion of the subject for fear that it will provoke 'hysteria'. The dominant tendency is to view eugenics as a purely historical phenomenon, and to minimise its relevance to current debates. Within the discourse of scientists, which is generally dominant in Britain, eugenics is seen as causing public fear of genetics, but this fear is generally seen by scientists and ethicists as due to ignorance or misunderstanding of genetics. The conventional view is that the eugenics movement of the first four decades of this century was based on 'bad science', or misunderstandings of genetics, and was the result of a peculiar set of social and political circumstances. The implication of this view is that now we know so much more about genes, and have witnessed the horrific consequences of eugenics, we will not make that mistake again.

There is some truth in the conventional view. Early

eugenic schemes were undoubtedly based on a crudely deterministic view of the role of genes which is now scientifically discredited, although resurgent in popular discourse (Nelkin and Lindee 1995) and a lack of understanding of the genetics of populations. It is also true that eugenics has acquired a very bad name in liberal political culture, although this has not prevented its re-emergence in traditional form in China. Events of the last five years in the former Yugoslavia and Africa have also reminded us of the ease with which 'ethnic cleansing' can happen. Nonetheless, in the advanced post-industrial democracies the resurgence of state-sponsored eugenics programmes is probably not a major threat.

It would be a serious mistake to assume, however, that because, at least in the liberal democracies, a return of state-sponsored eugenics is unlikely, that eugenics is no longer a threat. In order to appreciate this, eugenics must be understood as more than just a right-wing attempt to get rid of 'undesirable' people, using spurious scientific justification. The purpose of this chapter is to examine tendencies both within genetics itself, and in liberal free-market societies, which are likely to lead to a resurgence of a form of eugenics, which, although less brutal than the earlier version, may be no different in some of its consequences.

The Relationship Between Genetics and Eugenics

The received view of eugenics is that it is an abuse of scientific knowledge arising from genetics. This is premised on the traditional liberal model of science, that science is a 'value-free', objective quest after knowledge, for its own sake. According to this view, scientists are not responsible for the abuse of their work by politicians with malign intentions. Scientists are, however, required to accurately inform the public about their work, in order that it be properly understood, and measures taken to prevent 'abuses'.

This is not the place to embark upon a critique of this traditional view of the relationship between science and society: the critique has been adequately developed by many sociologists, philosophers and political activists. I will simply state that, in my view, the traditional view of science is not adequate. For example, at a philosophical level, 'facts' cannot be distinguished from theories, because theories are logically prior to any observation. At a practical level, those scientific questions which are seen as interesting, and therefore receive funding, are influenced by cultural, political, philosophical and economic forces, as well as by simple self-interest. In short, science is a social enterprise, permeated by social values. This necessitates a far more complex concept of scientific responsibility than that which currently operates, even amongst progressive groups of scientists. In the current context, however, the key point is that the idea that eugenics was some kind of aberration depends on the traditional, and inadequate, model of the relationship between science and society.

To achieve a better understanding of the relationship of genetics to eugenics, it is necessary to look more closely at the relationship between science and society. Science as we know it developed in the 16th and 17th centuries, in the period of overthrow of feudalism by the emerging bourgeoisie. This was a period of rapidly changing political, philosophical and religious worldviews. Many commentators have noted the formation of a distinct 'ideology of science', in that period, presented most explicitly in the writings of Francis Bacon. Bacon argued that the role of science was to uncover the workings of the natural world (often seen as much like an enormous clock), in order that its forces and treasures be harnessed for human benefit. Feminist and ecological critics have noted Bacon's misogynistic metaphors of nature and the way that he saw nature as something to be controlled and subdued, rather than listen to or worked with.

As part of its legitimating ideology, science has promoted the idea that knowledge is inherently good, and that the scientific urge is simply curiosity, the discovery of knowledge for its own intrinsic interest. This is the story told to children, who are indeed very curious about the world, in order to encourage them to embark upon scientific careers. The reality, as Bacon emphasized is that the purpose of acquiring knowledge is to control the world. Put simply, control over the physical forces of nature became the source of power of the emerging dominant group in society, the bourgeoisie, and so it has remained until today.

The idea that continually expanding knowledge, and ever greater possibilities of control, constitutes progress, and is necessarily good, has become the key defining feature of modern western societies, since the Renaissance. As sociologists such as Weber and Foucault, have observed, parallel to the creation of new knowledge has been a gradual process of rationalisation and increasing control over nature and over society in the form of scientific management, or bureaucracy. In modern societies, it is hardly possible to imagine life without rules and bureaucracies to enforce them, and new measures to solve social and political problems are very often couched in terms of rationalisation and 'standardisation' of the non-standard and anomalous.

The purpose of this excursus on the role of science in modernity is to emphasize that, in our society, an important aspect of science is to enhance control and order. In the case of genetics, the managerial tendency is expressed through eugenics, which, at its root, is the urge to tidy up the accidents and mess that arises from sexual reproduction. Eugenicists argue for 'improvement' of the overall human gene pool, but what really appals them is that the whole business of human reproduction is out of rational control, and is left to chance. The eugenicists of the early twentieth century often pointed out the care we take over the genetics of our crops and domestic animals: how can we do this, and yet be so careless about human reproduction?, they asked. This desire to bring human reproduction under control is the common factor between right-wing and socialist eugenicists, such as George Bernard Shaw, who saw eugenics as a progressive and humane aspect of modernisation.

The aim of this discussion of the relationship between genetics and eugenics is to refute the idea that eugenics was an aberration. In fact, genetics and eugenics are inseparably linked. Some form of eugenics is an inevitable consequence of the advance of the science of genetics, although the

political popularity of overt eugenics programmes will vary according to time and place. Viewed in this perspective, the popular eugenics movement of the early twentieth century was a highly damaging false start for eugenics. An auspicious set of political circumstances propelled it prematurely into the light, with disastrous consequences for its reputation. But the underlying social and psychological conditions for eugenics did not go away: the eugenics movement drew on a huge base of popular support, because the urge to eliminate reproductive mess is deep-rooted. In a society whose central vision of itself is steady progress towards a future of prosperity, based on greater control over nature, it is close to unthinkable that technologies which allow us to not leave things to chance should lie unused.

Laissez-Faire Eugenics

After the Second World War, state sponsored eugenics programmes became unpopular, although eugenics laws persist on the statute books of some American states. The post-war liberal resolution of the eugenics problem was to declare that the problem with eugenics was that outsiders (i.e. the state) were interfering with what should be a free choice. Freedom of reproductive choice was declared a human right and the problem was deemed solved. This consensus has been buttressed by the swing in medical ethics since the 1960s away from paternalism and towards patient autonomy in the doctor-patient relationship.

The official orthodoxy in medical ethics remains that there must be no interference in free parental choice regarding abortion of genetically disabled foetuses. Instead, parents are provided with genetic counselling in order to facilitate and inform their choice. If they decide that they will continue with the pregnancy, then they must be provided with the maximum support and information to enable them to care for their child. The provision of such genetic services is justified on the grounds that many parents will wish to abort disabled fetuses, such as those with Down's Syndrome.

(Interestingly, the consensus on free choice does not appear to extend to pre-conceptual and pre-marital genetic screening: there appears to be little opposition from medical ethicists to programmes, such as that in Cyprus, where couples cannot be married by the Church unless they submit to genetic testing for thalassaemia. Such programmes, on the contrary, are applauded by ethicists and geneticists for the dramatic decrease they have produced in births of children suffering from thalassaemia.)

In my view, the prevailing emphasis on free parental choice, rather than guaranteeing that eugenics will not return, opens the door to a different form of eugenics. The liberal consensus, in assuming that parents' decisions about reproduction are supposedly private, personal matters (mainly about whether they feel they could cope with a disabled child), divorced from the social realm, misses the degree to which the personal, as the feminist slogan has it, is political. In fact, such decisions are strongly affected by many social factors which militate against the birth of genetically disabled children. The combination of such factors amounts to a strongly eugenic pressure on both parents and doctors. Amongst these factors are:

Disability oppression There are several aspects of the way this affects parental reproductive decisions. Firstly, able-bodied people receive negative images of people with disabilities and general misinformation about what their lives are like. Doctors are particularly likely to be misinformed since they often see only the most severe cases of a particular disability, in clinical situations. Secondly, parents will be aware of the material aspects of disability oppression: insufficient welfare provision, inadequate access and discrimination. Lack of adequate welfare provision, in particular, will affect not only the child but may create financial problems for the family, as well as increased stress. Thirdly, parents will be concerned about how society will view their decision to either give birth to a disabled child, or refuse a test.

Sexism Having a child is a serious burden in a society which radically under-resources parenthood (which is the traditional reason for most abortions). Women, who still bear the vast majority of responsibility for childcare, are sharply aware that the extra burden of caring for a disabled child will fall on them.

Medical pressure Doctors, by definition are concerned to cure and prevent suffering, and have severe difficulties in countenancing a decision to place other priorities before this. This partly explains the considerable evidence of doctors pressuring parents in subtle and unsubtle ways to accept tests and abortions. Doctors in turn, particularly in the USA, are under severe pressure from the threat of 'wrongful life' law suits. Once it has been agreed that a particular test is part of the 'standard of care', doctors are more or less obliged to offer it. Tests are often presented as 'routine' and 'for the health of your baby'. Once a test has been taken, and information about disability is available, there is a strong presumption in favour of taking action. As I have argued above, there is a general eugenic assumption in modern western societies, in favour of preventing reproductive mess, wherever possible.

Thus, social pressures guarantee that allowing parents a 'free choice' results in a systematic bias against the birth of genetically disabled children, that can only be called eugenic. Kitcher (1996) has dubbed the current situation 'laissez-faire eugenics'. In its essence, the influencing of the genes of the next generation according to a particular set of dominant social values is no different from the earlier eugenics, although it is less violent and direct in its execution. The unchallenged existence of such a form of eugenics is, in itself, a major aspect of disability oppression.

The existence of these eugenic pressures is not in itself a sufficient argument for interfering in parental choice: there are very good arguments for preserving freedom of choice, once a test has been offered. But the existence of laissez-faire eugenics points to the need for renewed effort to tackle the factors which create eugenic pressures. To fail to do so is equivalent to an abandonment of commitment to ending the oppression of disabled people.

The Current Situation

In the 1990s a new set of circumstances, including scientific, technological and social changes, point to a radical and

disturbing expansion of laissez-faire eugenics over the next few years. The major development is, of course, the stunning successes of molecular biology, since the advent of recombinant DNA technology. Less often noticed in the context of discussions about eugenics are developments in reproductive technology. The successes of molecular biology have given it enormous prestige, even an aura of invincibility. As Nelkin and Lindee (1995) have documented, there is a gradually developing 'common sense' genetic determinism, which itself has extremely disturbing potential consequences.

A major impact of the new genetics is on medicine. As more genes are discovered which confer susceptibility to major diseases, the proponents of the Human Genome Project foresee a new golden age of genetic medicine. Our health and the health of our children will come to be seen as written in our genes, and the tools will become available for predicting the future health of children before they are born. Automation of genetic testing will eventually lead to the development of tests that will give an overall expected health profile. As genetics comes to dominate medicine, through testing and gene therapy, medicine will become, in large part, a regime of management and control of genes.

In this climate, the underlying presumptions of society against leaving things to chance will come powerfully into play. If we know that certain genes cause predisposition to common diseases, and it is possible to test for them, then a social consensus will rapidly develop that it is irresponsible to refuse to undergo tests. Natural parental wishes to give their child the best start in life, coupled with the urge not to leave things to chance, will be sufficient to ensure that such tests become routine. It will be seen as irresponsible and cruel to even consider bringing a disabled child into the world. We may soon start to hear that every child has the 'right' to a healthy genetic endowment.

The technical development which is likely to make widespread human genetic selection a realistic possibility is pre-implantation genetic diagnosis (PID), in which a single cell from an embryo is removed for genetic testing. PID has far greater possibilities for selection than prenatal testing and abortion, because it does not involve abortion of an established pregnancy. PID is performed in conjunction with *in vitro* fertilisation (IVF), which produces, on average, ten embryos, of which only two or three are implanted. Such embryos have a far lower moral and emotional weight than a foetus. We are already seeing the effect of this technology in influencing ethical decisions: in Britain a doctor has already been given ethical approval to perform PID for genes for familial cancers which can be treated. It is highly unlikely that this would be accepted for pre-natal screening and abortion, but because it is so much technically easier to achieve using PID, the question about which conditions justify prevention of birth is allowed to slide.

The crucial factor, which differentiates PID from termination of pregnancy is the number of embryos. Once presented with the genetic data for each of ten embryos, it will be very difficult for a parent to ignore the data and refuse to select. PID allows not merely the elimination of clearly harmful alleles, but the selection of embryos carrying the 'best' combination of alleles. This is equivalent to a shift from negative to positive eugenics. There is a danger that if PID were to become widespread, it would encourage a culture of choosiness regarding embryos.

The conventional response to such arguments is that PID is currently a medical procedure, which is far too invasive to become commonplace, involving as it does the risks, rigours and low efficiency of IVF. This may be a short-sighted view, however. The technology of *in vitro* oocyte maturation is developing rapidly, and it looks likely that in a few years it will be relatively simple to perform an ovary biopsy, containing hundreds of eggs, which can be frozen and matured at will. This will replace the current dangerous and unpredictable procedure of hormonal stimulation of ovaries. At that point, the only barrier to widespread use of PID will be the low pregnancy rate of IVF. However, a) this is probably not much lower than the pregnancy rate achieved in natural fertilisation; the difference is that it is much easier to make repeated attempts by natural methods, due primarily to the difficulties of obtaining eggs in current IVF; b) the pregnancy rate may be higher in women who have normal fertility; and c) scientific and technological progress will probably increase the pregnancy rate in IVF.

If oocyte maturation succeeds, therefore, IVF may become a much more accessible choice for normally-fertile couples. Given the possibilities that it holds for selection, PID may become the technology of choice for the conscientious couple who want to make sure they give their baby the best start in life.

At the same time as these scientific and technological developments are occurring, the political climate, particularly in the USA, is changing in a number of ways which will encourage eugenic outcomes. Firstly, there is an increasing pressure in all countries to reduce the costs of healthcare to the state. Politicians are looking for ways to cut healthcare budgets, and it is clear that preventing the birth of disabled children, with lifelong healthcare costs, is very cost effective. (It is true that genetic counsellors are opposed to putting direct pressure on parents in this way, but this is not necessary: in a situation where healthcare rationing is accepted, social pressure will suffice. The crucial decisions, about the introduction of screening programmes, will be taken by healthcare bureaucrats, under the influence of accountants. Once such programmes are in place, there is no need to posit biased genetic counselling.) The current political climate also dictates a reduction in welfare support, and this financial pressure on families will be exacerbated by the fear that they or their children will become uninsurable, unless they take genetic tests, although in the USA legal steps are now being taken to deal with this particularly blatant problem.

In largely private healthcare systems, such as in the USA, doctors come under direct influence from biotechnology companies anxious to make a rapid return on investment. In the USA, where genetic tests are unregulated (and likely to remain so in the climate of economic liberalism), companies are already selling tests which have not received ethical approval from patients' or medical organizations. Some ethicists, including some in the pay of biotechnology companies, argue that individuals have a right to any personal information that can be obtained by genetic testing. To refuse them this information is unacceptable paternalism, it is argued.

Conclusion

In summary, it seems that the combination of rapidly developing genetic and reproductive technology, free market capitalism, a liberal medical ethics and underlying eugenic patterns of thought are creating the conditions for a dramatic expansion of laissez-faire eugenics. Until now this has been largely a matter of preventing the birth of babies with Down's Syndrome, Spina Bifida and a few rare single gene disorders. In the future it seems likely that controlling the genes of our offspring will become an integral, even central part of most people's reproductive experience. In perhaps ten years time, it is possible to envisage a situation in which middle class professional couples will routinely undergo pre-nuptial genetic counselling or pre-conceptual and pre-implantation or pre-natal genetic testing, for genes predisposing to major diseases, as well as some more common single gene disorders. It will soon become common sense that sex is for fun, but having a baby is a serious matter, not to be left to chance. Although there will be a certain amount of state involvement, through cutting of welfare and its piecemeal and surreptitious replacement by genetic screening programmes, in line with liberal theory, change will be mainly enacted through the reproductive decisions of individuals. Everything will be done in the name of better health for our children, but the result, the shaping of the gene pool by social pressures and prejudices will be no different in essence from the former eugenics.

What can be done about this? Do we even want to do anything? For many people, the prospect of bringing reproduction under scientific control and improving the health of our children is wholly positive. If nobody is forcibly sterilised, what is the problem? It is necessary to state clearly why an expansion of laissez-faire eugenics is to be feared.

The most immediate reason is the effect that it would have on the liberation of disabled people. Certain philosophers, such as John Harris, have been at pains to emphasise that there is no moral inconsistency between compassion and respect for disabled people and attempting to prevent their birth. Although this may be true at a theoretical level, what it misses is that in the real world and in the minds of prospective parents, the two things are intimately related as discussed above. It is difficult to believe that in a society which had overcome its fears of disability and truly considered disabled people as equal members of the community, that there would be such an interest in pre-natal screening.

At present most able bodied people suffer from massive fear about disability, coupled with ignorance, misinformation and negative images. If people were aware of the reality of the lives of people with Down's Syndrome, for example, they would be much less likely to abort such foetuses, disability activists argue. To come into touch with such realities, and overcome fears of disability, will take a prolonged process of listening to disabled people and learning to accept their judgements of which lives are worth living. At present able bodied people have very little judgement about such matters. If, instead, we choose to ignore this obligation and proceed blindly with an expanding programme of genetic testing, ignoring our lack of judgement and the other eugenic factors which militate against the birth of genetically disabled people, we are essentially abandoning their struggle for liberation.

A second reason for opposing laissez-faire eugenics is the same as for the more old-fashioned variety: that the diversity of the human gene pool is an important value in itself. There are, furthermore, obvious perils in allowing large scale interference in the gene pool, the most obvious of which is where to stop. There is no clear line dividing disease from 'normality'. Many people, for example, would prefer their children not to have tendencies towards being fat; obesity is a risk factor for many diseases including heart disease and diabetes. Should we allow free access to genetic testing for obesity? We lack the knowledge of human biology to be able to judge the evolutionary value of genes, which in advanced western societies produce wide-spread obesity: in short we lack the wisdom to play God.

Thirdly, under a laissez-faire regime, it will be impossible to maintain a strict dividing line between serious medical conditions, more trivial conditions and non medical characteristics such as appearance, behaviour, aptitude and intelligence (assuming that genes influencing these characteristics can be found). Even now, it is accepted that women using private sperm banks wish to know the educational achievements, ethnic origins and athletic abilities of their sperm donor. The existence of a burgeoning market for cosmetic surgery and the prescription of growth hormone to normal short children with no hormone deficiency are further pointers towards future trends. The increasing emphasis in business on the importance of the quality of 'human resources' certainly seems likely to influence parents' choices about their offspring's genes.

A further reason is that once widespread genetic selection was in place, it would appear increasingly artificial to oppose direct intervention in the human germ line, once technology for doing so safely becomes available.

Finally, once widespread laissez-faire eugenics was practised, it would be easy for governments to subtly influence the process, not to eliminate particular social groups in the old-fashioned way, but to further goals of national policy, such as increased competitiveness and a lower healthcare budget. Laissez-faire eugenics could easily collapse into state-managed eugenics.

So, to return to the question, what is to be done? There are four elements which will contribute to the expansion in laissez-faire eugenics: advancing technology, free-market capitalism, liberal medical ethics and underlying eugenic predispositions.

The very first step must surely be to recognize the reality of laissez-faire eugenics and the seriousness of its impending expansion. It remains the case in most circles that the mere mention of the possibility that reproductive freedom might have harmful consequences evokes puzzlement or hostility.

In fact, it is time for a critical look at the way that the concept of reproductive freedom (particularly freedom from state interference in individual choices about selective abortion) is based upon free-market economic and political liberalism. The refusal to recognize the existence and harmful consequences of laissez-faire eugenics parallels free market economists' refusal to concede that the unrestrained

working of market forces can ever have harmful consequences for society as whole. It is time for a more thoughtful debate about these issues.

If we abandon our liberal spectacles, it is apparent that there is a relatively simple resolution to at least part of the problem. The right to freedom from interference in decisions made after a test has been taken should be maintained. However, *there is no basis for an automatic right of access to all tests that science has developed.* It is perfectly possible to maintain minimal and essential rights to freedom from outside coercion without allowing a testing free-for-all.

In essence the argument is not a moral or ethical one, and, in fact the emphasis in discussions about genetics, on the term 'ethics' reflects the liberal/individualistic terms of the debate. As the example of moral discussions about abortion and disabled people illustrates, addressing the issues in abstract ethical terms ignores the social and political realities, and therefore ends, I would argue, in moral mistakes. Nonetheless, the term ethics predominates, even where the issues, such as discrimination in employment and insurance are patently of public policy.

This is the case here. Arguing that there is a need to restrict access to genetic tests, according to socially agreed guidelines is not a question of paternalistically telling people that certain information is not good for them. Rather it is a matter of protecting the public interest. We are familiar, in other fields with the argument that unrestricted consumer choice is not necessarily a good thing. For example, most people would concede that the existence of a market for tropical hardwoods and hamburgers is not sufficient justification for unrestricted destruction of tropical rainforests. There is a larger public interest which, we would hope, will predominate over free trade.

There is a similarly vital public interest in preventing an expansion of laissez-faire eugenics, which is more important, in my view, than individual desire for knowledge and control. This approach is particularly essential if we are to prevent a slide into testing for trivial medical conditions, and ultimately non-medical characteristics. Society must assert its right to exert some control over the development of genetic testing and screening.

There must be a broad public debate on the question of which conditions justify termination of pregnancy. In current debates, the views of people with disabilities are marginalised and rarely heard: instead, the debate is heavily dominated by the views of scientists, doctors and medical ethicists. Such debates should be led by people with disabilities. My intention is not to propose legal bans or to morally censure those who opt for termination of disabled pregnancies. Ideally, the outcome of such a debate would be guidelines, with a certain amount of room left open for flexibility in particular cases. In the interim, we should adopt a policy of erring, if it is an error, on the side of caution: pre-natal genetic tests should be offered only for disorders which are fatal in childhood, or in which there is a very high degree of pain and suffering.

As Kitcher has argued, a second precondition of making the world safe for genetic testing is a commitment to combat those forces which make freedom of reproductive decision little more than a fiction. Some of those forces derive obviously from free-market liberalism, such as the penchant for cutting welfare and healthcare budgets. We must also renew our commitment to combating disability oppression and the sexism that dictates that the burden of care falls predominantly on women.

Finally, I believe that the current situation is positive in that it offers us the opportunity to re-open fundamental debates. Do we really believe that diversity of human life is an important value worth preserving? Is freedom of reproductive choice an untouchable absolute? Is the avoidance of suffering our overriding moral value? And if we have the tools, can we resist the opportunity to take control of something that looks messy and very uncertain? Tackling the latter question involves engaging with a fundamental critique of science, modernity and our ideas of progress.

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Ethics & Medicine (1998) **14:3**, 90–96 0226–688X

Book Reviews

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Brave New Families: Biblical Ethics and Reproductive Technologies
Scott B. Rae
Grand Rapids: Baker Books, 1996
ISBN 0-8010-2077-8, 247 pp., paperback $16.99

Scott Rae has written a comprehensive work which gives an overview and moral analysis of the latest reproductive technologies employed by the American fertility industry. While the book is non-technical enough to be generally accessible, it is still sufficiently detailed to constitute an informative and philosophically substantial evaluation of the ethical standing of contemporary assisted-reproductive methods.

The alphabet soup of emergent types of assisted reproduction that Rae navigates can be dizzying. From AIH (artificial insemination by husband) to AID (artificial insemination by donor) to GIFT (gamete intrafallopian transfer), ZIFT (zygote intrafallopian transfer), and embryo cloning, these biological manipulations raise basic questions about the nature of the human person and family. They perhaps serve as fodder for people interested in portraying them as mere social constructs. But through a sensitive integration of scripture, legal case precedent, and reason, Rae effectively argues that however sophisticated fertility science may become, full human personhood begins at the completion of conception. He also argues that the marriage-based heterosexual family is not only the biblical procreative model but is also objectively best for children, and hence an essential moral prerequisite for human procreation through whatever means. Any philosophy of procreation which does not embrace these themes cannot credibly lay claim to a firmly grounded biblical ethic.

Rae begins his book with an explanation for the increased rates of infertility among American women during the last 30 years. Later marriage, the delay of childbearing in order to pursue careers, increased incidence of sexually transmitted disease, and abortion are all contributing factors. Thus today 10 to 15 percent of all married couples in the United States are infertile, a rise of over 300 percent since the mid-1960s (p. 19). This largely socially-induced phenomenon—coupled with the powerful primal desire of human beings to have children—has created a fertility industry that generates more than $2 billion of revenue annually. Yet, this industry is generally unregulated, either commercially or ethically. This situation has given rise to alleged instances of moral malfeasance on the part of health care professionals, perhaps most significantly in the case of a University of California Irvine physician indicted on egg-stealing charges. This event post-dated Rae's writing, but underlines the prescience of his moral considerations. Indeed, the reality that technological competence has substantially outstripped genuinely probing moral reflection among many researchers and clinicians in fertility science is the defining feature of contemporary assisted reproductive practice.

Beyond limning the social context of developing reproductive technologies, Rae carefully reviews the contours of the American legal landscape. As with the biomedical technology, the law is rapidly evolving, and unfortunately is sometimes directed by judges imbued with the shallow, instrumentalist—but culturally dominant—understandings of human personhood and procreative liberty. But Rae effectively draws the distinction for the Christian couple between what is legally permissible and what is religiously permissible, reminding them that they are ultimately under God's dominion, not Caesar's.

Importantly, here and elsewhere Rae is eminently sensitive to the pain suffered by infertile couples, and to the existentially overwhelming nature of their desire to bear and raise children. In fact, it is this keen pastoral sense which is perhaps the most distinguishing characteristic of the book, and one which renders it practically useful, not only for academics, but for counsellors, pastors and interested laymen as well.

Hence, while he observes and respects the biblical ideal of natural procreation, he exegetes a scriptural ethic that allows for the responsible use of technologies like GIFT, ZIFT, AIH, IVF (*in vitro fertilisation*) and, more restrictively, AID. Rae's coverage of other strategies to combat infertility (egg donation, embryo transfer, surrogate motherhood and cloning) is similarly judicious, as he couches them in the larger settings of Christian virtue, the integrity of human relationships, and divine sovereignty.

Rae closes his study with chapters on prenatal genetic testing and maternal-foetal conflict. The former discussion is duly suspicious of the social consequences of routine genetic screening for birth defects. Rae writes, 'What kind of cultural ethos is being created by the growing prevalence of [genetic] testing and routine abortion when the results are not what the couple desires?' (p. 208). He points to the subtle devaluation of the disabled among us, and the gradual undermining of parental commitment to offspring as the inevitable result of such a practice. He holds that for the Christian who chooses to allow such screening, its morally proper use is to aid in preparation to receive and love one's child, not to provide information which may result in abortion. As well, Rae alludes to the pragmatic value of prenatal genetic testing from the physician's legal perspective: its liberal and even profligate use can help insulate physicians from litigation in the event of stillbirth, foetal deformity, neonatal dysfunction, various types of maternal distress, and other untoward outcomes.

Rae's review of possible maternal-foetal conflict scenarios is illuminating and perceptive as well, highlighting American society's doublemindedness and confusion concerning the moral standing of pre-born human beings. Rae rightly establishes that in the US legal abortion on demand is a *de facto* reality throughout the nine months of pregnancy, and then ponders the paradoxes of life-saving *in utero* foetal surgery, foetal murder laws, a woman's prospective postnatal liability for prenatal torts against her foetus once he has been born alive, and the occasional efforts of hospitals and physicians to compel medically indicated Caesarean births or treatment for drug-addicted pregnant women. Such are the ironies of an abortion culture that knows full well—but resists consistently acknowledging—the full humanity of the pre-born. Rae's inclusion of commentary on the socially and clinically corrosive consequences of the abortion license is appropriate, for it underlines an increasingly common reality in many first-world nations: the broad interrelatedness of medicine, politics and the law.

Rae's controlling conclusions—particularly that complete personhood is a reality from conception—will not sit well with the burgeoning fertility industry and its sometimes unrestrained boosters in academe. Yet, however unglamorous or financially inconvenient, this verdict provides a healthy check on the increasingly exotic array of artificial reproductive practices. Such curbs are a valuable reminder of the simple and socially preservational truth we all too readily suppress: the ability to apply a technology, or benefit from it, does not alone secure its moral justification.

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Ethics & Medicine (1998) **14:3**, 90–91 0226–688X

The Frankenstein Syndrome: Ethical and Social Issues in the Genetic Engineering of Animals
Bernard E. Rollin
Cambridge & New York: Cambridge University Press, 1995.
ISBN 0-521-47807-3, vii + 241 pp., paperback $18.95; hardback, $49.95

'As long as people schematize the issue of genetic engineering of animals as "all is permitted" versus "nothing is permitted," rational social progress on the issue is impossible' (pp. 10–11). Bernard E. Rollin's intent in exploring the issue of genetically engineered animals in *The Frankenstein Syndrome* is to explain, and then explore, the ethical and social issues involved. His goal is to determine which issues are of relevant concern, and which are based on unfounded, irrational thinking. Dr. Rollin does an excellent job dissecting the various philosophies underlying the views for and against genetic engineering of animals. He examines

the risk to animals associated with such technology, and finally outlines a new, and reasonable social ethic for the use of genetically engineered animals in research and agriculture. Rollin examines a broad spectrum of information, and his writing style makes this book very readable for anyone seeking to better understand this important topic.

The book begins by exploring the ethical issues and philosophies involved in 'doing science'. Science as a discipline prides itself in being 'value free'. The author explains the danger of such reasoning, and points out that science must actually be based on certain 'epistemic value judgments (i.e., value judgments about what ought to count as knowledge and proper methodology for achieving knowledge)' (p. 18). Epistemic value judgements are made, for example, in choosing the types of experiments to be performed, and in determining what data is important and what is not.

He further points out that although science claims to be independent of moral judgement, the basis of scientific activity—what is funded versus what is not; the types of experiments that are performed; and the way in which animals and humans are allowed to be used for study—are all based on social morality. Rollin then examines many philosophical viewpoints concerning genetic engineering in chapter one. On the issue of 'playing God' he concludes that 'mere theological concerns do not serve as a basis for asserting in the social ethic that genetic engineering is intrinsically, morally wrong' (p. 24). However, just because a concern has some theological basis does not imply that it is not valid.

On reductionism, Rollin argues that although reducing all life to its chemical, physical, genetic composition, without regard for individualism, is wrong, it does not logically follow that genetic engineering is wrong because it is inherently connected to reductionism. On the contrary, not all genetic engineers hold to reductionist theory. The author goes on to discuss the more relevant problem that scientists simply ignore ethical considerations either because they are not taught to think in that way, or because they are too focused on the advances of science, neglecting to think about the consequences of those advances.

Rollin dissects other arguments against genetic engineering in this chapter as well, including the arguments of species integrity, the dualism of nature versus convention, environmental philosophy, and the mixing of human and animal traits. He concludes that all arguments claiming that genetic engineering is inherently and intrinsically wrong fall into two categories. They are either based on religious values that cannot be 'translated into secular moral terms' (p. 66), or they are based on the idea that genetic engineering is wrong because it will have bad consequences. Neither category, in the author's opinion, is substantial enough to deem genetic engineering entirely wrong or detrimental.

Dr. Rollin moves from an examination of the philosophical arguments in chapter one, to a discussion of the risks involved with genetic engineering of animals in chapter two. This chapter is based on the notion that genetic engineering is wrong on the basis of the 'unknown but inevitable dangers it entails' (p. 68). The author claims that because scientists hold to the notion that science is 'value-free,' they tend not to think about the consequences of their actions. Instead, they are enthralled by the excitement of the chase—science for the sake of science. Rollin states that this is understandable in the context that 'any human activity, pursued with genuine passion, resists retardation, even for the most rational reasons' (p. 69).

In this chapter Rollin rightly points out that scientists too often minimise or ignore dangers associated with their research. He gives examples of actual cases where scientific endeavour has produced accidental, yet devastating negative consequences. Rollin does a good job of bringing to the reader's attention the fact that no new technology is risk-free. Clearly genetic engineering of animals carries risks, and clearly one's value system will determine the risks one takes, even in everyday living.

The author's solution to assessing these risks, however, seems to point toward more public involvement. This he believes can be accomplished through public education, dialogue, and public hearings aimed at establishing communication between scientists and the community at large. In turn, Rollin suggests that this will create an atmosphere where more of the risks will be thought out before science continues forward without regard to the consequences of its actions. He puts forth a model in which public hearings about genetic engineering are first held all across the country, after which a list of the major concerns and ways in which these risks can be minimised is drawn up in 'lay language'. The second phase of the model would include the formation of federally mandated committees of people from all walks of life to judge proposals for genetic engineering of animals based on the risks drawn up in phase one. Research proposals would be accepted or rejected on these grounds.

Rollin is convinced that the public can comprehend the basis of genetic engineering and make educated assessments of what research should or should not be carried out. Although it is true that 'the experts' are often 'arrogant' and don't consider the consequences of their work, it is equally questionable that the public would do a better job in risk assessment. After his lengthy discussion on the importance of public involvement in decision making, Rollin discusses specific risks involved in genetic engineering of animals, including safety of the final product, narrowing of the gene pool, genetically engineered disease models, environmental dangers, military applications, and socio-economic risks. This second chapter deals well with the specific risks discussed. However, the way in which Rollin proposes to deal with creating policy for genetic engineering leaves some room for criticism and questions concerning its feasibility.

The final chapter of Rollin's book deals with the 'plight of the creature' (p. 137). He addresses the best interests of the experimental animal versus those of society as a whole. Rollin discusses the traditional uses of farm animals and the social ethic for the treatment of these animals, which was focused on useless cruelty. This was because farm animals, under traditional care, were free to live in environments suited to their nature (i.e. cattle and chickens roaming free and provided with food, water, and shelter).

Rollin then examines the traditional cruelty ethic as not being adequate to handle the moral issues of today in terms of proper treatment of animals. 'Most animal suffering is not the result of people trying to inflict suffering, but rather the by-product of people pursuing socially acceptable, even desirable, goals . . .' (p. 148). This is the author's premise for putting forth ideas to form a new social ethic for the treatment of animals. Rollin discusses 'factory farming' in detail—the use of antibiotics and vaccines to allow animals to be housed in confined spaces, etc. He then explores the possibility of genetically engineering animals that would be content to be housed in these confined spaces, and thus would not suffer as a result of this practice.

Rollin defines his view of animal ethics as a belief that proper treatment of animals is a duty which should be legally mandated. It should include laws against housing and using agricultural animals against their natures, provide for regulation of new uses of animals based on their well-being, and should protect the animals used to prevent pain and suffering as much as possible. The author discusses animal rights in the context that they 'protect individuals and their natures from being eroded for the common good' (p. 159). He points out that most of society is not against animal use, but rather wants the animals used to be treated in the best possible way.

In this final chapter of the book, Rollin covers a lot of ground in discussing a new ethic for the treatment of animals in both agriculture and research. His new social ethic calls for the restriction of suffering. In terms of genetically engineered animals, he believes that animals that are to be genetically engineered for the benefit of humans should not be worse off than the parent stock from which they were derived. If possible, they should be better off than the parent stock. This principle Rollin terms 'conservation of welfare.' After examining this principle, Rollin discusses the usefulness of creating laws to uphold the 'conservation of welfare' ethic. This last chapter then goes on to examine the use of genetically engineered animals in agriculture, and as disease models in research, and ends with a discussion on the controversy of animal patenting.

Rollin concludes his book by pointing out that genetic engineering is a tool that humans will use, but the way in which it is used is dependent on us and our values. His goal for this book rests in its ability to convey knowledge about the issues involved in genetically engineering animals in order to help the public make wise decisions concerning this very powerful technological tool.

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Ethics & Medicine (1998) 14:3, 91–92 0226–688X

Medicine in the Bible and the Talmud: Selections From Classical Jewish Sources
Augumented Edition
Fred Rosner
Hoboken, NJ: KTAV Publishing and Yeshiva University Press, 1995
ISBN 0-88125-506-8, xiii + 328 pp., hardcover $29.50

Originally published in 1976, this second edition has been 'augmented' and is a third

larger than its original. Dr. Fred Rosner, a Professor of Medicine at Mt. Sinai Hospital in New York, has a rich background in Jewish medical ethics which he has shared previously through international lectureships, numerous publications, and as the Chairman of the Medical Ethics Committee of the Medical Society of New York State (p. xi). The result of his scholarship is a book presented in five parts: a general introduction; a review of specific diseases; a word study of specific organs mentioned in Scripture and the Talmud; a discussion of specific foods and life-style; a comprehensive section on physicians, ethics and prayers; and miscellaneous subjects of interest under the umbrella of Biblical and Talmudic medicine.

Early in the text, and serving as a foundation of Dr. Rosner's worldview perspective, is a chapter written by Suessman Munter (p. 7). Foundational to this perspective is the quote, 'only God could heal sickness' (Gen. 20:17; Num. 12:13; Exod. 15:26). Thus, the physician becomes a helper deriving strength from the Divine power who is identified in the Torah. Rosner expresses gratitude to another pioneer in the field of Hebrew medicine, viz. Julius Preuss. Preuss was a physician of repute and a learned Hebrew scholar who published a landmark historical study in 1894 entitled, *The Physician in the Bible and the Talmud.*

The discussion of specific diseases contained in the Old Testament and Talmud is enlightening. Some of the earliest thinking regarding haemophilia is contained in the Babylonian Talmud, which suggested that it was uniquely transmitted to male offspring. Many centuries later haemophilia would be proven to be linked to the X chromosome. The important ceremony of circumcision was contraindicated in those families whose sons previously had a bleeding event during the procedure, which we now know was a direct result of haemophilia. In fact, ranking preservation of life as superior to even the Sabbath and circumcision, Moses Maimonides in his Mishneh Torah observed, 'it is possible to circumcise later than the proper time but it is impossible to restore a single [departed] soul of Israel forever' (p. 44).

Similarly, the highly contagious nature of rabies was articulated in the Talmud. Clothes coming in contact with rabid animals were destroyed. It was even permitted to kill rabid dogs on the Sabbath, again to protect the sanctity of human life. The illness of King Hezekiah receives medical scrutiny (Isa. 38:1ff, 2 Ki. 20:1ff; 2 Chron. 32:24 ff), although its exact nature cannot be unequivocally ascertained. The discussion which ensues in the Biblical texts suggests he had leprosy, or abscesses, more specifically, a peritonsillar abscess.

Much of Rosner's discussion of specific organs relates more to their figurative or metaphorical use in Scripture and the Talmud. For example, hearts may be described as 'uncircumcised' and the gallbladder seen as the seat of bitterness. However, the Talmud provides one of the earliest and most accurate anatomic descriptions of the spleen and notes that a ruptured spleen in animals will only respond to splenectomy. This is a very reliable medical observation which was not achieved in other manuscripts of a similar era.

The foods section discusses the ramifications of kosher. In addition, an entire table is provided with Talmudic reference to the healing efficacy of chicken soup. In fact, Moses Maimonides had written extensively on this topic in the thirteen century. Those in the medical profession have always had a high regard for Maimonides's religious integrity and medical knowledge. Consistent with this impression, Maimonides's contraindications to the common practice of 'blood-letting,' are medically accurate (p. 153). Also, his choice of foods after blood-letting are most appropriate for restoration of depleted iron stores resulting from the procedure.

The section of the book committed to ethics is exceedingly valuable. Rosner begins by placing the doctor-patient relationship squarely in a Scriptural context with the mandate, 'heal, He shall heal' (Exod. 21:14–20) and 'neither shalt thou stand idly by the blood of thy neighbour' (Lev. 19:11–16). Again, he focuses on the vertical relationship between God as healer and physician as instrument. He buttresses this perspective with a quote from Ben-Sira, 'from God a physician getteth wisdom' (Eccl. 38).

Rosner's exposition of visiting the sick (Bikkur Holim) describes a real ministry to those suffering. 'In addition to cheering the patient up and encouraging him to get better, the visitor would cook and clean and perform other tasks . . . Jewish law requires that the visitor pray for the recovery of the patient, either in the latter's presence or not' (p. 176). The authority for this ministry to the sick is obtained from God's visit to Abraham after his circumcision (Gen. 18:1) which is offered as an example that must be emulated (Deut. 13:5).

The Oath of Asaph (3rd to 7th Century AD) is reproduced (pp. 184–6), showing it has much in common with the Hippocratic Oath. The physician is enjoined under this holy oath to proscribe euthanasia, abortion, sexual activity with patients, and to hold all taken in confidence. The vertical dimension of the oath is summarised thus: 'be mindful of Him at all times and seek Him in truth and righteousness.' The prayer of Maimonides is also provided, along with a discussion of scholarly work produced on its authorship. In light of the Oath of Asaph and Maimonides's prayer, Rosner's chapter on suicide is well done, emanating from a concern for the sanctity of all human life.

Finally, general subjects provide closure to the text. Rosner has an interest in the enigmatic poisoning of the Israelites by quail contained in the 11th chapter of Numbers. However, his cursory one page handling of the episode relegates more of the incident to mystery than scientific explanation. Poisoning by quail in Mediterranean climates has occurred throughout history and has been studied by Maimonides, Sargent, Ouzounellis, and most recently Rizzi. The rapid mortality in the Israelites described in the Biblical text appears to be related to the quails' prior ingestion of hemlock resulting both in a curare-like paralysis and resultant respiratory arrest in human subjects ingesting spring, migratory quail. The bibliography at the end of this chapter is incomplete and does not do justice to the amount of work performed in this area.

Explicating the quail incident in scientific terms (Num. 11), much like describing the judgement of the Philistines as bubonic plague (1 Sam. 5; 6), in no way minimises Yahweh's sovereignty. From a believing physician's or scientist's perspective, such explication represents Yahweh's sovereign choice of disease to render his judgement.

Discussion of Job's disease is conspicuous by its absence. For many years it was fashionable to simply ascribe Job's malady to leprosy (*Nutrition and Health* 1996;11:73–78). But many dermatological presentations of leprosy (e.g. the 'tuberculoid' form) are associated with dysesthesia thus lessening or obviating any skin discomfort. An absence of such skin discomfort seems inconsistent with Job's presentation and course described in Scripture. Job was afflicted 'with *painful* sores from the soles of his feet to the top of his head' (Job 2:7). Erythema nodosum may complicate leprosy, but is most common after treatment, and causes pain. Overall, Job's terrible discomfort would seriously question leprosy as the appropriate diagnosis. For this reason, 'Job's Syndrome' (*Lancet* 1966;1:1013–1015) is now the title of hyper-immunoglobulin E syndrome with eosinophilia, which characteristically presents with painful skin lesions and recurrent abscesses.

Suffice it to say, Job's disease is fertile ground for medical musing and discussion, but was untouched by Dr. Rosner. There is also not much detail about leprosy itself—a critical disease in both Old Testament and Talmudic times. The chapter discussing the therapeutic efficacy of prayer is also noteworthy, but has unfortunately not been updated since the first edition. There is a much richer and more recent bibliography in this area than is provided. Even though the text is augmented and not revised, chapters such as the one on prayer should have been updated for impact.

Lastly, syphilis, or a syphilis-like disease, is alluded to by Rosner three times. To implicate syphilis as a disease in either the Old Testament or Talmud is unfounded since it is a disease first described when Columbus and his sailors returned from the New World (R.E. McGrew, *Encyclopedia of Medical History*, MacMillan Press, London, 1985; pp. 329–334; and *New England Journal of Medicine* 1991;325:414–422).

Rosner's book provides a rich compendium of Hebrew medical history from both the Old Testament and Talmud. Unfortunately, many of his chapters have not been updated since the first edition, and significant omissions in both the choice of diseases and relevant bibliography appreciably weakened the text.

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Ethics & Medicine (1998) **14:3**, 92–93 0226–688X

Christian Healing: What Can We Believe?
Ed Ernest Lucas
SPCK London 1997
ISBN 1-901443-00-0 202pp £12.99 Pb

So many books on the subject of Christian healing have been published in recent years that it is difficult to justify yet another. But it must be said that this one, though variable in quality, is more satisfying than most. It arose out of a series of conferences attended by Christian health-care professionals, pastoral workers, theologians and ethicists, coming from different traditions of Christian healing ministry. The editor, Dr Ernest Lucas, was until recently Education Director of the London Institute for Contemporary Christianity and is now Tutor in Biblical Studies at Bristol Baptist College.

The chapter headings give an idea of its scope. 1. How are people healed to-day? The relationship between the 'medical' and the 'spiritual' in healing. 2. The Church's ministry of healing. 3. What is health? towards a Christian understanding. 4. The significance of Jesus' healing ministry. 5. Suffering. 6. Psychiatry and religion. 7. Growing old and dying. Each chapter is written jointly by a medical practitioner and a theologian.

For the reviewer, the best chapter is the one on a Christian understanding of health. The authors, Professor Duncan Vere of the Royal London Hospital and the Rev Dr John Wilkinson, author of the classic monograph 'Health and Healing', published in 1980 by Handsel Press, Edinburgh, are both renowned for their careful Biblical exegesis and rigorous thinking. They trace out the concept of health in the Old and New Testaments. They emphasize that in the Bible, health is a quality of the whole human being, that it is the gift of God, that Christ came to bring 'life in all its fullness', and that the source of human health lies in having a right relationship to God, to oneself, to our neighbours, and to our environment. They emphasize that health is the gift of God, and that appropriate medical intervention, whether by drugs, surgery, vaccination or radiotherapy, simply improves the conditions for natural healing to occur. Health is not an end in itself, but a means to an end: that end being, as the Westminster Shorter Catechism puts it, 'to glorify God, and to enjoy him for ever.'

Scattered through the book, there are references to the demonic and the power of evil. Particularly valuable is the contribution of Dr Bill Lees who worked for eighteen years as a doctor and church-planter in South East Asia with the Borneo Evangelical Mission and who writes from first-hand experience of the phenomenon. Elsewhere in the book, there is a warning about making a mistaken diagnosis of demon possession.

Several contributors deal with the important pastoral question: How should we pray for those who are ill? The subject of services for prayer and healing is considered fully and helpfully in the chapter on The Church's ministry of healing. Various options are described in some detail: adapting regular services, liturgical and non-liturgical healing services. Several contributors deal with the important matter of cooperation between health care workers and hospital chaplains. In general, chaplains seem to be more open to working with medicals than medicals are to working with chaplains.

There is a good chapter on Psychiatry and Religion. The psychiatrist acknowledges the common Christian distrust of psychiatry, and traces this to the earlier psychiatrists' misunderstanding of religion. But he reports that, in the UK at least, the situation is changing. A recent survey of psychiatrists in London teaching hospitals revealed that 40% believe in God and 20% attend church on a regular weekly basis. He does not believe that Christians should insist on seeing a Christian psychiatrist. Any good psychiatrist should be prepared to accept a request that a patient's central religious belief should be respected.

The final chapter, on growing old and dying, is a sad one. Written jointly by a nurse who lectures in palliative care and a hospice chaplain, it expresses deep concern over what they perceive to be the growing secularisation of care for the dying. The authors report the findings of a working party set up to examine the impact of the hospice experience on the Church's ministry of healing. It came to the conclusion that God is defeated by suffering; saying: 'It is through this every day experience of suffering that we have glimpsed the dark side of God, and cannot in all honesty tame the terror of that experience. God is seen to be very destructive in the working out of his purpose.' Thankfully, the authors wholeheartedly reject this view. Nevertheless, this is a trend which calls for watchfulness and prayer.

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Ethics & Medicine (1998) **14:3**, 93–94 0226–688X

The Ethics of Human Gene Therapy
LeRoy Walters and Julie Gage Palmer
New York & Oxford: Oxford University Press, 1997
ISBN 0-19-505955-7, xviii + 209 pp., hardcover $29.95

'What we shall be has not yet been disclosed.' (1 Jn. 3:2, Revised English Bible)

The apostle John's words could form a fitting commentary on the current state of human genetic engineering. Public awareness of this complex field has burgeoned since the advent of Dolly, the cloned Scottish sheep. *The Ethics of Human Gene Therapy* by LeRoy Walters and Julie Gage Palmer attempts to 'describe the science of gene therapy in terms easily accessible to laypeople and to examine the major ethical questions that are raised' (p. xvii).

To that end, after an introduction which describes the plight of David, the 'bubble boy' afflicted with Severe Combined Immune Deficiency and the efforts made by gene therapy to treat him, Chapter One presents an overview of genetic function and heredity. The authors make a clear distinction between somatic cell therapy (affecting only the patient) and germ line therapy (which is passed on to descendants).

Chapter Two describes somatic therapy in more detail, including techniques and vectors involved, and diseases amenable to somatic gene therapy. Several major ethical questions concerning gene therapy research are presented and discussed.

Chapter Three progresses to the more controversial side of germ line therapy. This approach presents greater technical problems than somatic cell therapy. 'The germ-line gene therapy "patient" will be, at most, a zygote or preimplantation embryo at the time of gene transfer. (We do not regard sperm and egg cells as patients in any sense of that term)' (p. 66).

The potential usefulness of germ-line therapy is discussed, and compared to other options, such as somatic cell gene therapy. 'Germ line gene therapy . . . will probably be more risky and complicated' (p.74). 'Prenatal diagnosis followed by abortion is already a widely used method of preventing genetic disease,' they write, although '. . . these strategies do not attempt to treat the affected embryos or fetuses' (p. 75). Germ line gene therapy may present an alternative to this 'search and destroy' approach.

Germ-line therapy should not be regarded as a panacea: 'As long as germ-line gene therapy must be performed on human zygotes and embryos one at a time after *in vitro* fertilization, it is likely to remain an expensive technology with limited use' (p. 76).

Arguments favouring germ-line therapy—both for individuals and as a potential benefit to the human race—are discussed. The authors emphasise the prevention of disability and disease, cure if prevention is not possible, and coping, if neither prevention nor cure is available. Although both authors 'think that abortion is morally justifiable in certain circumstances,' they are opposed to the 'halfway technologies' of prenatal diagnosis and selective abortion and preimplantation and selective discard. These say to parents: 'There is nothing effective the health care system has to offer. You may want to give up on this fetus and try again'; and to people with disabilities, 'If we health professionals and prospective parents had known you were coming, we would have terminated your development and attempted to find or create a nondisabled replacement' (p. 82).

The spectre of eugenics proves impossible to avoid.

Chapter Four tackles the difficult issue of genetic enhancement—the altering of capabilities or characteristics to improve function, like size, sleep, ageing, memory, aggression, and cognitive abilities. These are divided into intellectual and moral categories.

Both authors are qualified to address these subjects. Dr. Walters holds three academic posts (including professor of Christian ethics at Georgetown University) and served for twenty years on the NIH Recombinant DNA Advisory Committee. Julie Gage Palmer is a lawyer. Surprisingly to my mind, for a book on ethics, although the authors mention morals and offer their opinions, the basis of their conclusions seems nebulous. They are based more upon public opinion polls—a fluid and insubstantial basis for decisions of the magnitude that face us in the realms of genetics. For example, '. . . it is better for human beings to possess [the ability to use germ-line intervention] and use it for constructive purposes like preventing disease in families than not to possess the ability. The central ethical issue is public accountability . . .' (p. 86). While public accountability is important, is it really a 'central ethical issue'? Certainly, from a Christian standpoint, this lack of basis is disappointing.

Admittedly, the authors don't rely exclusively on public opinion: '. . . the results of public opinion polls and trends in expert opinion do not determine whether germ-line genetic intervention is morally right or wrong. At best, these surveys and policy statements provide supportive evidence for the moral judgments of others who have thought about this issue, either briefly or on a more sustained basis' (p. 91). How are moral judgements to be made? What is the basis from which these 'others' form their opinions? The authors leave these questions unanswered.

The authors are clear in the presentation of both their views and other opinions, even to the point of disagreeing with each other. But I am left with the impression that they state their views without saying why, or how those views are based. This is not to imply that those views are necessarily misguided, illogical, or faulty

(in fact, I agreed with many of them), merely that they struck me as being issued in a vacuum.

The section on moral genetic enhancement brings up the idea of morality without religion. 'Moral traits are clearly related to many genes . . .' (p. 123). This seems to me to confuse the issue of behaviour with motives and morality, even though the authors do not deny the use of religion for moral improvement: '. . . genetic enhancement, as we have described it, would be directed only against a few of the most violently aggressive tendencies in human beings. . . . there would be ample opportunity for continuing moral improvement within one's chosen religious tradition and community' (p. 128). Religion is thus seen as perhaps a second-rate treatment to be used in less severe cases.

Does altering behaviour (by changing genes) thereby change morality? I am reminded of what the author of Proverbs wrote: 'As a man thinks in his heart, so is he' (Pr. 23:7, KJV). We remain in ignorance of many of the workings of genes. It is well to remember that both nurture and nature play roles in our formation, and that genes frequently provide influences, not determinants.

The authors are rightly opposed to any form of mandatory genetic intervention (and discuss who should be making decisions regarding gene therapy), and envision voluntary social programs. L. S. Rosenberg in a review published in the *Journal of the American Medical Association* (278.3, July 1997, p. 252) suggests that this view may be 'dangerously naïve.'

Chapter Five provides a review of public policies, and is followed by five appendices and an index. In summary, I found *The Ethics of Human Gene Therapy* to be an excellent introduction to this complicated topic, and well worth reading and considering. The authors' approach may be overly optimistic, and I would have liked to have seen evidence of a greater foundation for their ethical judgements.

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Ethics & Medicine (1998) **14:3**, 94–95 0226–688X

Organ Transplantation: Meanings and Realities
Edited by Stuart J. Youngner, Renée C. Fox, and Laurence J. O'Connell
Madison, WI & London: University of Wisconsin Press, 1996
ISBN 0-299-14964-1, 299 pp., paperback $22.95

This book is the outcome of a project sponsored by the Park Ridge Center for the Study of Health, Faith, and Ethics. Scholars were invited from broad disciplinary backgrounds (art, literature, history, religion, philosophy, anthropology, folklore, sociology, psychology, psychiatry, and surgery) as well as from various religious traditions (Jewish, Catholic, Protestant, Buddhist, Confucian, Hindu, and Shinto) to, 'explore the phenomenological reality of organ transplantation and examine its human and cultural meaning' (p. 3). Common to their approach was the avoidance of positivism, resulting in a careful evaluation of numerous belief systems and their impact on health-related concerns. The authors took the 'phenomenological point of departure' (p. 21), and focused on the meaning of an object (or more specifically, the entire spectrum of objects associated with transplantation) rather than the object's place in the material world. The book itself is an effort to describe the experiences of the entire transplant enterprise in a manner free from the drawbacks inherent in scientific inquiry.

It is not at all surprising, especially considering the manifold backgrounds of the authors, that the essays varied substantially in the value of their subject matter for a Christian audience. This particular book review is written from the perspective of an Evangelical physician interested in transplantation ethics and the care of transplant patients and their families. Therefore, three essays were especially informative, which is obviously a narrower focus than the scope of the book as a whole. The three essays will receive the brunt of discussion, with a shorter summary of the other essays to follow.

Ruth Richardson, a Wellcome research fellow in the History of Medicine, wrote the chapter entitled, 'Fearful Symmetry: Corpses for Anatomy, Organs for Transplantation?' She provides a valuable perspective in positing that transplantation is a recent development in a much longer historical process. In fact, the evolution of modern surgery was dependent upon dissection of cadavers and therefore is a fertile historical parallel to the contemporary retrieval of organs from dead donors. Indeed for Richardson, this is the *fearful symmetry*. The ethics surrounding the disposition of corpses for anatomy first raised the issues of financial incentives and presumed consent. Many of the contemporary concerns about illegal trafficking in transplantable organs mirror preceding ethical parallels in Great Britain at a time when poor individuals were worth more dead as dissection specimens than they were when alive. The wealthy could afford reinforced caskets as a defence against grave robbing (called burking) at a time in history where there was a great demand for the 'parts' of the recently deceased. In fact, this was the first time that social value criteria were applied to the retrieval of bodies or their parts.

Even then, the dissection of corpses was viewed as beneficial in the abstract, but undesirable in the particular. Today, the same may be said for donating organs. Richardson observes a dying scene from a bygone era in need of cadavers for dissection: 'on his death bed a body snatcher, Jack Hall, is attended by a "swarm" of twelve doctors, whose interest in his demise is evidently much greater than in his survival' (p. 78). Many individuals would paint the same picture of the terminal care those dying with potentially transplantable organs receive today, framed against a milieu wherein ten people on transplant waiting lists die every day.

Richardson drew upon another prior symmetry which had direct impact on the ethics of asystolic protocols for organ donation. She observes that in some Victorian hospitals, dissection was done with 'indecent if not dangerous haste' (p. 80). What follows is strong ethical criticism of the same haste applied to the titrated death of asystolic donors. Physicians both now and then may ally themselves 'too closely on the wrong side of the life-death divide' (p. 81). A final parallel between cadavers for dissection and the transplant enterprise is decried as an 'almost predatory obliviousness to the source of organs.' Organs are to be obtained without bribery or coercion and only then do they mirror a decent society.

A conservative Rabbi, Elliot N. Dorff, wrote 'Choosing Life: Aspects of Judaism Affecting Organ Transplantation'. He observes that transplantation is not simply a matter of changing parts of a machine but also involves our deepest feelings, our broadest conceptions, and our core values. He then applies Old Testament Scripture to undergird his further observations about the impact of transplantation on Hebrew culture. Drawing from Lev. 18:5, *pikkuah nefesh*, the obligation to save people's lives emerges and allows for the concept of organ donation. The obligation to one's fellow man as *hesed* is also developed from Deut. 11:22, Ex. 34:6–7, and Deut. 13:5, with the definition of 'an act done out of loyalty to one's fellow'. To Dorff, these Scriptures influenced Jewish life so thoroughly 'that they inevitably constitute part of the psychological background that prompts Jews to think seriously about donating'. His summary statement, 'the clear mandate of the Jewish tradition . . . is that if organ donation can be done . . . Jews must lend a hand in seeing to it that it is done' culminates in the over-arching use of choose *life* from Deut. 30:19–20 as a call to ethical organ donation.

Renée C. Fox, a long-time contributor to the ethics of transplantation wrote 'Afterthoughts: Continued Reflections on Organ Transplantation.' She expresses concern about 'the premise on which organ transplantation in the U.S.A. is currently proceeding: the "not-totally rational beliefs that transplantation is an unequivocal and unconditional good way of sustaining lives, and that the more organs proffered, procured and transplanted the better"; the "death is the enemy" to "be overcome" outlook that energizes these medical-surgical acts; and the hubris-ridden unwillingness to recognize and consent to our human finitude that this perspective implies' (p. 252). To Fox, inhabiting this quote is 'our triumphalist temptation to slash and suture our way to eternal life.' Like Richardson, she provides valuable ethical concern regarding asystolic protocols. She reviews two such protocols (the University of Pittsburgh and the Regional Organ Bank of Illinois), discerning major caveats. The protocols seem to demonstrate 'dramatically and disturbingly . . . how an evangelical attitude toward transplantation combined with zealotry about procuring organs and unwillingness to accept limits, can involve grave violations to the moral practice of medicine' (p. 267). Fox's essay is timely and consistent with grave concerns in the Christian community focused on the area of asystolic donation.

Other important data emanating from other essays in this volume are contrasts with the transplantation enterprise in Japan. During a year in which 2,000 heart transplants were performed in the United States of America, none were done in Japan. This is a result of the lack of validation of brain death as death in Japan. In fact, Denmark finally accepted brain death in 1990, leaving Japan as a unique culture in transplantation discussions.

For those who utilise narrative in the teaching of ethics, Fiedler's essay 'Why Organ Transplant Programs Do Not Succeed' is a helpful review. Old standards for discussion, such as

Mary Shelley's *Frankenstein*, Bram Stoker's *Dracula*, Robert Lewis Stevenson's *Dr. Jekyll and Mr. Hyde*, and H. G. Wells' *Island of Dr. Moreau* are mentioned with the helpful addition of recent fiction like Robert Silverberg's *Caught in the Organ Draft* or Larry Niven's *The Patchwork Girl and Jigsaw Man*. The core of these works is the transplant-minded physician portrayed as an enemy of traditional beliefs. The traditional beliefs in question involve fragile bodies and inescapable mortality. Final warning contained in this literature review from Fiedler includes, 'none-the-less, at a deeper level of the psyche, the dark side of our old ambivalence about the quest for immortality keeps suggesting that perhaps the whole strategy is wrong . . . Surely such a conviction underlies the covert rejection of transplantation' (p. 65).

For those who value a phenomenological approach to the issue of transplantation, especially in an effort to avoid the more typical positivist evaluations, this book makes for interesting reading. Furthermore, it stands to remind the reader that those outside the Evangelical mainstream are just as concerned about asystolic protocols as we. Comparative religious classes also stand to benefit from the exposition of cultural and religious thought, especially eastern, in some of these essays.

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Ethics & Medicine (1998) **14:3**, 95–96 0226–688X

Strong Shadows: Scenes from an Inner City AIDS Clinic
Abigail Zuger
New York, NY: W.H. Freeman and Company, 1995
ISBN 0-7167-2916-4, xvi + 243 pp., hardcover $22.95

Dr. Abbie Zuger is an AIDS doctor. One might think that all doctors would be AIDS doctors, but most doctors are not actively involved in the ongoing care of AIDS patients. It is true that the major professional medical societies have endorsed a democratisation of HIV care. But it is also true that the overall care of HIV patients requires a level of medical expertise, commitment, and altruism that few physicians possess. Because of the variety of infections that HIV patients can acquire as the disease progresses to AIDS, infectious disease specialists are the physicians of choice for the sickest AIDS patients. But even so, many infectious disease specialists situate themselves, geographically or institutionally, so that they will not have to provide such care. And many generalists who could otherwise upgrade their skills and join the effort follow suit.

The burden of HIV care then falls on the few remaining ID specialists who like Dr. Zuger practise in areas where AIDS is endemic. AIDS specialists are like cancer doctors; they treat a dangerous disease with drugs which require careful monitoring. Dr. Zuger alludes to this in her story of Deborah Sweet, a patient who has a drug abuse history and whose arm veins are scarred.

Dr. Zuger draws blood through the femoral vein (the previous GP was too genteel to go beyond superficial attempts to obtain blood).

Over the course of our acquaintance, Deborah has slowly caught up on most of her routine screening blood tests, including her syphilis serology (negative), her hepatitis serology (positive), and her T-helper cell count (disturbingly low at 19). The white blood cell called the T-helper cell is one of HIV's major targets for destruction, and the number of these cells that have disappeared from the circulation correlates fairly well with an infected person's degree of immunosuppression. If their T-helper-cell counts are in the normal 500 to 1000 range, most HIV-infected people fight off infection quite well. The further their counts fall below 100 to 200, the more vulnerable to infection they become. I looked at Deborah's T-cell results for a long time when they showed up in my box. The process of coping with the vigorous, powerful, endlessly resourceful Deborah tended to move the real reason for our acquaintance to the very back of my mind, but here was an inescapable reminder. (p. 9)

The capsules and pills we lavish on our patients are almost all miniature time bombs. One patient in a hundred will develop reactions to them that may be life-threatening or permanently disabling if not picked up in time. The complications of HIV, another time bomb, can sometimes be anticipated and minimised by timely blood tests too. Blood is a vital part of the unwritten contract binding us all together in our strange, troubled marriage of the ill and the well. Without blood, everything begins to fall apart. (p. 170)

But blood also carries the virus which has caused so much death, illness, fear, pain, and loathing. So how will we get more physicians involved in AIDS care? This is not easily answered, and the purpose of this book is not to be a polemic about the medical politics of AIDS care. Dr. Zuger is an excellent, strong, unemotional writer. The book is a collection of patient encounters over time, each one dated, recorded, and organised as if there were a metaphorical camera running during the office visit. The author's hope is that her work would help middle and upper middle-class readers begin to understand that her patients are fighting more than a virus: 'Medical crises are juggled with dozens of others: court dates and parole violations, fostered-out children and strung-out parents, vandalized apartments, errant bullets, empty refrigerators, disconnected phones. The medications we judiciously prescribe are as likely as not to be sold on the corner for the price of a week's groceries or bartered for "better pills, you know, the ones my brother gets" or for a bag of dope' (p. xi.).

As one reads *Strong Shadows* one begins to appreciate the determination and courage of these patients amidst the chaos (strong shadows?). And one also better understands the reasons for the corresponding crisis in providing good care. One needs an insider's view to illumine this world, and Dr. Zuger gives us one.

Often the difficulties inherent in the care itself make the physicians seem like heroes, and the nurses, social workers, and clinic assistants appear to be altruistic superstars. What motivates them?

I went through each of the patient's stories in the book looking for the turning point, the sweet spot for the doctor. I was not disappointed, although if one is accustomed to instant cures and easy gratification these returns may seem too meagre to justify the struggle. But I think Dr. Zuger and her colleagues would point out that the sicker the patient, the wider the gap between patient and doctor, and the more one feels like a healer when a connection is forged. And the harder it is to forge a connection, the more one knows when one has fought the good fight with and for the patient, when one has kept company. Examples of significant encounters with patients follow.

Deborah Sweet:
'. . . no one short of Jesus himself is likely to persuade her down to the emergency room this afternoon. We lock eyes for a second.
"You're very angry today, Deborah."
". . . {Doctor} you can just give me eardrops. I'll wait outside." (p. 22)

Michael Soto:
'It is turning out that almost every week for the last year has had a Soto day in it, because Mr. Soto is in fact almost never pretty good . . . he has a set of remarkably complicated lungs that have been tormenting him for years . . . sometimes he is coming down with bronchitis, sometimes with pneumonia. . . .
"So!" I say after his chart finally works its way to the front of my stack and he is sitting in the exam room. "How are you feeling?"
"Good! Pretty good!" (pp. 36–7)
Cynthia Wilson:
' "So tell me what you had to eat yesterday."
Cynthia Wilson grins widely and settles back in her chair. I find myself grinning too. I actually don't care much about the vitamin and calorie counts I pretend to tally up these days. I just love watching Cynthia enjoy her food.' (pp. 90–1)
Eddie Rios:
' "You have a positive TB skin test?"
He nods, starts to drum again.
There. I have gathered a piece of information. At this rate we will grow old together.' (p. 116)
Anita Lewis:
' "A discharge in your vagina?"
"Yes, just [give me], you know, whatever cream you would use for a little sore."
". . . Let's have a look." . . .
"Oh, no, I just don't have time for that. . . ."
She sighs, gets up on the table, pulls down her underclothing, closes her eyes.
"Oh, my God." The words are out before I can stop them. Her vaginal area is a mass of sores, oozing and crusted. She has the worst case of vaginal herpes I have ever seen.' (p. 155)
Shannon Gallagher:
[A woman with "fictitious" AIDS, treated for several years by physicians as if she had the disease; Dr. Zuger draws blood for the test and waits for the result.]
'Her negative HIV test took three weeks to return. . . . I called a friend of mine at Pelham hospital, where Shannon [told me she] had had her first episode of PCP. He pulled her chart . . . Shannon had never had any kind of pneumonia at Pelham.' (pp. 188–9)
Jose Morales:
' "Well, at any rate, Dr. Grossman is back next week. . . ."
Mr. Morales's face is dissolving in abject misery. . . .

"Mr. Morales?"
He shakes his head, unable to speak.
"Mr. Morales?"
"I can't stay with you?"
"But you missed him [your former doctor] so much! You . . ."
He stays with me.' (pp. 209–10)

These are the moments which keep Dr. Zuger going. As she writes in the epilogue, 'After Mr. Soto died I took a brief vacation from the clinic. I missed him very much. It was beginning to seem that wherever I turned ghosts were at my elbow, gaunt faces and bodies I knew as well as my own. I couldn't see a new patient without the old ones crowding in. But after a few months away from the clinic the serenity became very empty. I am now back at work' (p. 240).

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Ethics & Medicine (1998) **14:3**, 96 0226–688X

Medical Ethics Today: Its Practice and Philosophy
British Medical Association 1993
ISBN 0-7279-0817-0

The aim of this book is to be a practical guide, primarily for doctors, which reflects contemporary ethical thinking. Since its inception the BMA has aimed to promote standards of good professional practice and contribute to the discussion of ethical issues. This is the fifth in a series of texts on medical ethics published by the BMA. It is a useful work of reference to which everyone concerned with medical ethics should have access. Despite the fact that the text is primarily a working tool for doctors, it has relevance for those working in other fields, for example, theology, philosophy, law and health care administration.

Each of the chapters considers a broad area of ethical concern: consent and refusal; confidentiality and medical records; children and young people; reproduction and genetic technology; care for the dying; cessation of treatment, non-resuscitation, aiding suicide and euthanasia; treatment and prescribing; research; doctors with dual obligations; relations between doctors; inter-professional relations; and rationing and allocation of health care resources. The final chapter, serving as a conclusion, attempts to explain the philosophical reasoning behind the guidance given in response to the ethical queries.

The strength of the text lies in its structure and organization. For convenient use, the main areas of discussion are briefly indicated at the beginning of each chapter and a summary of conclusions is given at the end of each chapter. Each chapter is subdivided into numbered sections and subsections. For example, chapter 4 considers reproduction and genetic technology; section 4:3 considers abortion and subsection 4:3.1 examines BMA policy and background to the abortion debate. The well organised table of contents and the detailed index enable the text to serve as an excellent reference source.

The unifying theme in the text is the concept of partnership between doctor and patient, a relationship that might be described as 'medical friendship'. This insight that friendship is at the core of the doctor-patient relationship finds its most lucid articulation in the Hippocratic oath. The Hippocratic tradition of medicine gives pre-eminence to the doctor's responsibility in the relationship to 'benefit the patient and to abstain from whatever is deleterious and mischievous'. The Hippocratic tradition of medicine speaks across cultures and generations precisely because it has at its centre the healing relationship between the doctor and the patient. Ethics is concerned with the good. Aristotle in his *Nichomanachean Ethics* highlights that 'Every art and every investigation aims at some good'. It is the health of the patient which is the good achieved through the doctor-patient relationship. The doctor practises his or her art for the benefit of the patients in the form of health, the human good achieved through the doctor-patient relationship. Thus medicine is linked with the first science of human good, that is, ethics. As such, medicine is inherently ethical because of this good which the doctor-patient relationship aims at. In this theme Hippocrates encouraged that every doctor should also be a philosopher.

The underlying ethical theory supported by this text is the principle of autonomy. As such, medical ethics is seen as something dependent upon an individual outlook. Flowing from this principle of autonomy, the right to choose is considered to be the primary ethical principle of our cultural milieu. In such an ethical context medicine has become a mere facility, where the doctor serves the wishes of the autonomy of the patient (including the right to kill or to be killed). Civil law is today the best mechanism to sustain this conception and practice of medicine. For example, in the BMA's view espoused in the text, doctors with a conscientious objection to providing contraceptive advice or treatment have an ethical duty to refer the patient promptly to another practitioner or family planning clinic. This governance of medical practice by the civil law removes from the medical profession its rightful ethical independence. The art of medicine practised by conscience-governed doctors has been reduced to a series of procedures regulated by civil law.

The Hippocratic tradition of medicine does not primarily serve society, or the state, or the law, or the family, or the autonomy of the patient. The doctor serves a patient in the unique covenant relationship of healing, with the health of the patient being the doctor's primary consideration. The goods of truth and freedom constitute the very subject matter of medical ethics, establishing the foundations of the very nature of medical care itself. The art of medicine summons doctors to be guardians and servants of life. Such sentiment is best expressed by Hippocrates; '*where the art of medicine is loved, there also is the love of humanity*'.

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